

2019

Transitions of Care Toolkit

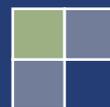
Developed by the Forum of ESRD
Networks' Medical Advisory Council
(MAC)

This toolkit for health providers and practitioners is a reference tool that gives information about challenges in transitions of care and suggestions to help create solutions.

Tell us what you think!

Please take a moment to complete a short questionnaire about this Toolkit. We appreciate your insight and suggestions to make our resources better.

<https://www.surveymonkey.com/r/ForumResEval>



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This Toolkit is a guide, created by experienced professionals using the available evidence, produced by the Medical Advisory Council (MAC) of the Forum of ESRD Networks. The MAC anticipates revisions and additions to the Toolkit overtime. The Toolkit is meant as a resource and should not be referenced as a regulatory statement. As with other MAC Toolkits (QAPI, Catheter Reduction, Medication Reconciliation, Vaccination and Medical Director Toolkit) this document is meant to help guide medical directors in meeting their obligations.

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CHAPTER 1. INTRODUCTION AND GUIDE TO USING THIS TOOLKIT

This toolkit gives health providers and practitioners information about challenges in transitions of care and suggestions to help create solutions. It is a reference tool, not something that requires reading from beginning to end.

The toolkit is unique in several ways.

- It describes several transitions of care that patients identify as being challenging or otherwise important.
- It describes details of problems that providers report about transitions between settings.
- The suggested solutions are “actionable.” In other words, they are actions that a dialysis clinic can implement that do not require major policy or staff changes.

Chapters 1 through 3 discuss the reasons to have a toolkit and provide background about patient engagement and provider responsibilities. Chapter 4 describes several transitions of care that can be challenging or unsafe as identified by patients and providers. Chapters 5 through 9 include brief introductions about the transition and examine challenges of the transition in more detail. Also provided are suggestions about what a dialysis clinic can do to solve the problems. Finally, chapter 10 is devoted to steps in evaluating and solving problems.

The annotated appendix includes background articles and studies, as well as publically available templates and online resources.

How to Use the Toolkit

Use this toolkit as a reference. Expand it, modify it, and use it to fit your needs.

- Use any of the specific transitions to develop quality improvement projects for your clinic.
- Use selected chapters or subsections to highlight particular issues to your staff members even if you do not use them for quality improvement projects.
- Use relevant sections in your patient care planning. For example, if a patient is making a transition from one modality to another, review that section in the modality change chapter.
- Use some of the ideas here to improve processes without gathering the whole team. For example, it should not take the whole team to decide to assign the administrative assistant to manage voice mail so that important communications are not missed.
- Include patients in your team. Ask patients to share their perceptions. Often they have insights and suggestions that providers do not have.

We suggest first reading chapters 2-4, as these short chapters frame the issues. Then read introductions and review highlights of problems that patients and/or providers encounter. Find out what the dialysis

team, including patients, considers important. Consider what resources are available to your clinic and what the most critical safety issues are. Depending on problems, review the suggestions for solutions.

The team may come up with problems and solutions that are different from ones identified in this toolkit. Your focus can be broad or narrow. Use this as a guide to address other transition challenges that are not included here.

Fixing everything at once is not realistic. The dialysis clinic cannot fix all the problems. Spend your energy on things that are within your control or influence.

Solutions should prompt creating processes that are “embedded” in activities of the dialysis clinic. A process should not depend on one individual who, for example, has excellent communication skills. It could fall apart when that person is not present. However, that person should help the team identify important aspects of communication and create a “template” for use by all clinic staff.

Look outside the clinic for help with creating processes that work. For example, work with a nurse at a home health agency to create communication processes for their kidney failure patients. Consult with other clinics within your organization to find out what they are doing.

Key Concepts:

1. Identify transition problems that are important to the clinic and solutions that are “actionable.” When a solution that works to improve a transition is found, embed it as a process in the clinic’s routine workings.
2. Include patients on the quality improvement team. Ask patients about their experiences and perceptions.
3. Use this toolkit as a guide to stimulate ideas about what transitions are most critical in the clinic and what can be done. It is dense with information, but still not exhaustive. Break the information into pieces that you can digest and use. Working on everything at once is not realistic.

Definitions and Abbreviations

Definitions

Dialysis providers or dialysis staff: These are staff persons who are employed by the dialysis clinic, including the clinic administrator, nurses, patient care technicians, dietitians, social workers, administrative assistants, and anyone else who has a part to play in patient care.

Dialysis team: The team is made up of patients, nephrology practitioners, and dialysis staff. In some contexts, the term refers only to the providers and practitioners.

End-stage Renal Disease (ESRD): This is the term for kidney failure severe enough that the person will die or have serious medical complications without renal replacement therapy.

Family: “Family” is used as an umbrella term that covers immediate family members, as well as significant others and close friends who make up the patient’s support system. In the case of pediatric patients (under 18 years old), “family” refers to the adults who have legal responsibility for the patient, whether they are the patient’s biologic or adoptive parents or legal guardians.

Kidney patient: This term is used for a person whose kidneys have failed to the point that dialysis or transplantation are required in order to live; the person is often referred to as an “ESRD patient.”

Nephrology practitioner: This term is used for nephrologists, nurse practitioners, physician assistants, and clinical nurse specialists who specialize in the care of kidney patients and are certified to make treatment decisions, write orders and prescriptions, and give medical advice. The Medical Director of a clinic is a nephrologist.

Practitioner or Clinician: This term is used for physicians, nurse practitioners, physician assistants, and clinical nurse specialists that can include both persons who are specialized in nephrology and those who are not (e.g., primary care providers or hospitalists).

Renal Replacement Therapy: This is treatment used to maintain life for patients with kidney failure, including in-center hemodialysis, home hemodialysis, nocturnal hemodialysis, continuous ambulatory peritoneal dialysis (CAPD), continuous cycling peritoneal dialysis (CCPD), and kidney transplantation.

Abbreviations

Abbreviation	Meaning
CAPD/CCPD	Continuous Ambulatory Peritoneal Dialysis/Continuous Cycling Peritoneal Dialysis
CKD	Chronic Kidney Disease (not severe enough to require renal replacement therapy (RRT))
ED	Emergency Department (or emergency room (ER), generally at a hospital)
EMR	Electronic Medical Record (computerized medical record, also referred to as EHR, electronic health record)
EMS	Emergency Medical Services (ambulance services)
ESRD	End Stage Renal Disease
HIE	Health Information Exchange
HIM	Hospital Information System
HIPAA	Health Insurance Portability and Accountability Act; these are federal regulations meant, in part, to keep medical information private and secure.
HD	Hemodialysis (in-center, home, or nocturnal)
HHD	Home Hemodialysis
LTAC/LTCH	Long Term Acute Care/Long Term Care Hospitals; these are hospitals that care for patients who are too sick to be in a skilled nursing facility (SNF), but no longer require the services of a traditional hospital. They generally offer rehabilitation services. Most patients, though not all, have the expectation of returning home or going to an SNF. They may offer dialysis on site, but some send kidney patients to an outpatient dialysis unit for RRT.
PCT	Patient Care Technician
PCP	Primary Care Provider

PD	Peritoneal Dialysis (CAPD or CCPD)
PDSA	Plan-Do-Study-Act (methodology)
QAPI	Quality Assurance and Performance Improvement; this process is used in many organizations, including dialysis clinics, to identify and evaluate problems in quality of care, devise solutions to those problems, and evaluate whether the solutions put in place made a difference.
RN	Registered Nurse
RRT	Renal Replacement Therapy
SNF	Skilled Nursing Facility; this is commonly known as a nursing home. Some patients are in an SNF for long-term care. Others are there temporarily for rehabilitation and expect to go home once they are able to do so.
UF	Ultrafiltration
USRDS	United States Renal Data System; this organization collects and analyzes large amounts of information about dialysis, transplantation, hospitalizations, etc., annually.

CHAPTER 2. WHY DO WE NEED A “TRANSITIONS OF CARE” TOOLKIT?

Kidney failure creates the need for many transitions for patients. These include starting treatment for kidney failure, changing the type of treatment, or being hospitalized and returning to the dialysis clinic. Each change, like a transplant or a shift to home dialysis, can cause stress and fear for patients. This toolkit is designed to help understand and improve these transitions. As professionals, we must go beyond simply considering the transitions between settings of care (e.g., hospital to dialysis clinic). We also need to understand the experience of that and other transitions from the patient’s perspective. We need to understand how changes in care affect patients and their families.

Why do we have a Toolkit?

This toolkit describes some of the key transitions of care from both the kidney patient and dialysis team perspectives. We examine why the transitions may be difficult and suggest ways to improve them and make them safer.

There are questions we should ask about transitions and how they affect our patients:

- What are care transitions?
- Why are safe transitions important?
- What is unique about care transitions of patients with CKD and/or kidney failure?
- Who is responsible for making a care transition successful?
- How do we know if a transition has gone well?

What is unique about kidney patients?

Transitions of care are the “movement patients make between healthcare settings as their health conditions and care needs change.” For kidney patients, healthcare settings may include:

- One or more dialysis clinics
- Home dialysis
- One or more transplant clinics
- One or more hospitals
- A skilled nursing facility (SNF)
- A rehabilitation center
- A long term acute care facility (LTAC)
- Home health care
- Supportive care (palliative care)
- Hospice
- Outpatient services

Care transitions are complex. If we miss steps in the process, patients may not get what they need. Consider the example of a patient with heart failure who leaves a hospital without the right prescriptions and instructions to take his medicines correctly. He may require re-hospitalization because of medication errors.

Many programs strive to improve the transition from a hospital stay to home or to an SNF or a rehabilitation center. We measure their success by how often a patient is re-hospitalized within a short time. Many hospital programs have resources that a dialysis clinic does not have. They may use pharmacists who can follow up on medications after a patient goes home. They may have a “nurse navigator” who checks in with the patient and family to see if their needs are met. In this toolkit, the focus will be on transitions that the dialysis team can control—or at least influence.

There are not many publications about care transitions of patients with CKD or kidney failure. We know that these patients are hospitalized more often and are more likely to be re-hospitalized than other patients are. We know that they tend to have multiple health problems and are on multiple medications. We also know that they see many providers who may not know about the unique nutritional and medication needs of kidney patients.

Patients with CKD or kidney failure undergo unique transitions that affect their quality of life, well-being, and safety. Hearing the diagnosis of kidney failure changes the patient’s life. Patients see new medical practitioners and may not even know why they are there. Even those who receive information about RRT options feel lost and often frightened. They do not know how their day-to-day lives will change or what the treatments will feel like. They often do not know what to do to take care of themselves. The dialysis clinic becomes central to the lives of many patients. This is particularly true for in-center HD patients who generally come to their appointments 156 times per year.

Once treatments start, patients and their families encounter lifestyle changes. Patients will have special diets and medications. Their schedules will change, and they may not know how they will keep their jobs and pay their bills, or get to and from the clinic. They face loss of control over their bodies and have an unknown future. Family members may need to take time away from work or childcare. Patients who choose home dialysis must accommodate new equipment and supplies in their homes.

Many patients grieve trying to cope with changes they face starting dialysis and/or getting a transplant. Friends and families may not understand why they cannot go on with normal activities, including work. Patients and their families can be socially isolated due to the time and energy demands of their new lives with kidney failure.

Many patients change from one treatment modality to another, whether by choice or necessity. Practitioners and dialysis staff must anticipate transitions between modalities and prepare patients for them.

The transition from one setting or RRT modality to another may seem routine to providers and practitioners. However, patients often say that they feel insecure and vulnerable when they need to make a change. Having new nurses and technicians is unsettling. Patients fear complications—and even loss of their dialysis access—when a new staff person cares for them. We do not know how often changes in staff lead to avoidable hospitalizations, loss of access, or other complications.

Adolescent and young adult patients have the added burden of transitioning from a pediatric model of care to an adult model of care. In the former, adults manage communications, appointments, and

medications. They make decisions with or without consulting with the child. In the adult model of care, we expect patients to manage their own health care. Other persons, including parents, are involved only if the patient gives permission. Pediatric to adult transitions are complex and will be discussed in a separate chapter.

What do we need to do to have good transitions?

Successful transitions depend on clear communications. Nephrology practitioners and dialysis staff need communication and empathy skills that may have been overlooked during school or training. Training largely focuses on the complex skills and knowledge needed to provide the dialysis treatment.

The dialysis team should know some basics:

- Patients come from many cultures. English may not be their first language. Hospitals and other settings often teach cultural awareness, but dialysis clinics may not have the resources.
- Patients with low literacy and/or health literacy may not understand their disease and the terms well enough to make choices that fit their lives. Even highly educated patients may not know the concepts and words used by the dialysis team.
- How things are said can have a profound effect on patients, who are often fearful of treatment complications. The language that is used makes a difference. The patient or family may not understand joking to a patient or to another staff member.
- Uremic and overwhelmed patients do not learn or retain information well. Information often needs to be repeated and written down for patients and families.
- The first communication with a patient sets the stage for the future. It has been said that if the first comment you make alarms the patient, he or she may not forget that experience.
- One of the common complaints that patients make about their care is lack of respect by their care team. This includes minimizing patient concerns about transitions.
- Patients often fear change. It does not help the patient to tell him or her not to be anxious or afraid. Fears of change should be acknowledged and discussed.

We know that many communication problems in clinics stem from time pressures. Frustrations about difficult situations also play a role. Dialysis staff and practitioners want to do the right thing. They do not wish to cause fear in patients, but may do so unintentionally. While this toolkit will not teach communication skills, it should give an insight into issues that affect patients. Social workers can help staff communicate respectfully and effectively with patients who may be angry, fearful, and/or anxious.

How do transitions of care affect providers?

While it is not the focus of this toolkit, patient transitions can affect the team. When a patient starts dialysis, the care team must assess him or her in a short time. The family may not be there to help learn about medications, healthcare needs, treatment details, social support, and healthcare history. Key data may be lacking, but quickly taking care of a stressed and “shell-shocked” patient who is going through a complex set of changes is necessary. At the same time, managing other patients with multiple serious conditions is required. Some of the urgent needs include:

- Help the patient get an access.
- Help the patient with money concerns, diet support, and medications.
- Assess the patient's short- and long-term needs.
- Repeat options education, even if it was done before the patient started treatment.
- Obtain new or changed orders for the dialysis prescription, medications, and other instructions that may not have been received when needed.

Changes in clinic ownership and/or EMRs can be stressful. Either of these can require new policies and procedures that take time away from patient care.

In the next sections, we will look more closely at each of the “players” in this drama of care transitions. We will share the survey results of patients and providers that show which transitions matter most to whom. We will give tips for how and when to intervene to improve those transitions. You can customize the suggested solutions for your clinic's needs. Our list of transitions and approaches is not exhaustive—but it provides a starting place.

Take Home Messages:

1. “Transitions of care” are not just about discharges from a hospital. Kidney patients and their families have many unique transitions—including a massive shift in what they expect for their futures.
2. Kidney failure does not go away, though its treatment may change. Both patients and providers must be ready for change, including different renal replacement therapy options.
3. Changes that seem routine for provider staff may be highly stressful for patients. Acknowledge and discuss the patient's fears with him or her. Do not minimize fear.
4. Communication is critical. Using easy to understand terms will reach the majority of the patients regardless of literacy or health literacy levels.
5. Respect is essential.
6. This is a complicated life journey. Many people interact with the patient. Clear, coordinated communication is key to success.

CHAPTER 3. WHO SHOULD USE THIS TOOLKIT AND WHO IS IT ABOUT?

This toolkit is by nephrology practitioners, dialysis staff, and patients for practitioners and staff. Care teams and patients may have different views of each transition. Knowing how the perspectives and values vary will help providers and practitioners guide patients through complex changes.

Who is the Dialysis Care Team?

Members of the dialysis care team include:

- Dialysis nurses
- Patient Care Technicians
- Social workers
- Dietitians
- Practitioners, including nephrologists, physician assistants, clinical nurse specialists, and nurse practitioners
- Patients
- Others in the clinic, such as a pharmacist or case manager (not available in all clinics)

Outside the clinic, there are:

- Primary care providers
- Medical subspecialists
- Transplant team
- Interventionists, either at the hospital or at an access center
- Pharmacy staff
- Skilled nursing and rehabilitation staff
- Hospital doctors
- Case managers
- Inpatient dialysis and hospital nurses
- Home health nurses and aides

The outside healthcare providers are not under the direct control of the dialysis clinic. Thus, working with them may require unique strategies and strong communication processes.

It is the job of the nephrologist of record to make sure the different individuals of the patient's care team are working together.

Who are the "Customers"?

Patients, whether they are "engaged" or "non-engaged" in their care, are the customers of the dialysis clinic. Families are involved to varying degrees and are often critical to decisions about care. In the case of pediatric patients, the family is always a critical part of care decisions.

While going through this toolkit, think about what approaches can be used with engaged or non-engaged patients. One size does not fit all.

Engaged patients take active and/or pro-active roles in self-management of their chronic condition(s). They work to understand their disease and its treatments. They process information, decide how it fits into their lives, and act on those choices. They “own” their disease and work as partners with their care teams. Engagement arises out of a positive interactive relationship with the care team.

Patient engagement can aid a successful care transition. An engaged patient can share data between providers, though this role is not ideal. An engaged patient can be more active in self-management of kidney failure and other health problems during a high-risk care transition. He or she may be more likely to report symptoms or concerns.

Disengaged (non-engaged) patients do not want to (or cannot) be active members of the care team. It is not the same as a lack of interest or failure to know the seriousness of the disease. It is also not the same as non-adherence to a treatment plan. A disengaged patient may adhere perfectly to the plan. Many times, fear of the disease, the treatment, or of the future can keep a patient from being engaged. Sometimes the relationship with the provider or practitioner does not encourage engagement. For some patients, having someone take care of them and make choices for them can let them put off facing their fears.

There are many reasons for non-engagement. Some patients may speak a different language. Cultures can vary. Education level can play a role. Others may feel that the care team always knows best. Patients may fear reprisal if they disagree with the care team. They may be so overwhelmed that they shut out any new information. They may be depressed.

Help Engage Patients in Their Care:

1. Offer HOPE that patients can have a life that is worth living, even with their health problems. Share stories of other patients or find “buddies” to help them see that their lives are not over.
2. Seek out what motivates them so you can help them to achieve their life goals (e.g., being there for children or grandchildren, more education, pets?).
3. Show respect.
4. Support autonomy (self-directed choices).
5. Educate them to feel competent and equip them to take on self-management tasks, such as following a meal plan or taking medicines the right way.

For transitions of any kind, responsibilities of the Care Team include:

1. Communicate with each other and with the patient. Talking to each other is best. Written communications are vital when:
 - Orders are given
 - Patients are given new instructions or prescriptions
 - Information is shared with non-dialysis care providers

2. Assess each patient's characteristics and needs, including:
 - Level of engagement
 - Health literacy
 - Level of self-management
 - Cultural differences
 - Social/family support
 - Goals of treatment (e.g., get a transplant, be as comfortable as possible, live long enough to see the kids graduate, continue working)
 - Readiness to hear information
 - Depression
 - Fear and anxiety

3. Be sure that the patient knows why the care team needs to have *all* healthcare information. This includes all medicine changes made by other practitioners, diet changes, new doctors, herbal or over the counter remedies, etc.

Giving the patient a personal healthcare history booklet may help.

4. Be clear with the patient about what dialysis can and cannot do. Patients need to know what their options are and why certain things are prescribed (e.g., a fistula rather than a catheter, phosphorus binders, sodium restriction).

5. Respect patient goals, choices and individual differences.

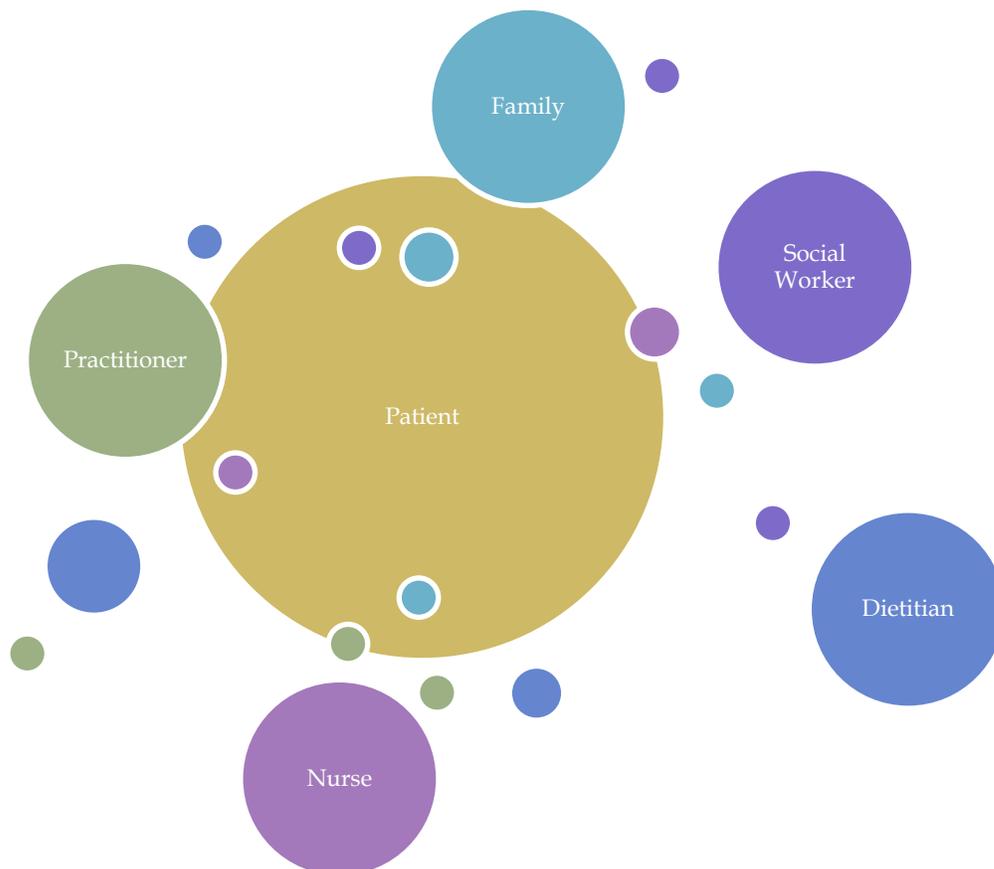
6. Share the treatment options and the prescription plan.

Tell the patient that that he or she may choose to change treatment modalities. Patients and their loved ones need to know that some treatment modalities may not work out. PD or a transplant may fail, for example. Other changes may occur as time goes on. These may include the dialysis schedule, the dialysis staff, the length of time that dialysis takes, or the type of access.

Why is Patient-centered Care Important for Transitions of Care?

Patient-centered Care means that care is given in a way that focuses on each patient's values and preferences. Information is shared with patients—and, with their permission, family members, care partners, and other medical professionals—to promote shared decision-making. This will help the patient reach lifestyle and health goals. Patient-centered care is an ongoing process, and patients' goals may change over time.

The center of all care transitions is, of course, the **patient**. The patient is the only one who feels the whole continuum of any transition. However, there can be additional administrative or clinical factors going on of which the patient is not aware. Practitioners, nurses, social workers, dietitians and others all have work to do to make any transition succeed. The family is also involved, jointly with the patient, by their support or nonsupport of the patient and/or via separate communications with providers. Shown here is a diagram of the various relationships for one patient. The diagram will look different for patients with strong family support or for a patient who has a strong relationship with the social worker.



In some cases, the needs and/or wants of the patient are *not* aligned with the needs of the family, which can greatly affect a care transition. The care provider may be in the unenviable role of referee. The first impulse often is to say that the needs/wants of the patient should always outweigh the needs/wants of the family. But we know that patients' wants and needs cannot always be achieved. Providers and

practitioners need to focus on logistics and feasibility of the care plan. This said, the care team needs to advocate for the values of the patient when realistic.

Why are many transitions difficult for patients?

- Lack of understanding of the treatment plan
- Not being included in making the plan or goals in the first place
- Being overwhelmed and dazed
- Anger and/or depression
- Lack of resources (e.g., transportation)
- Discomfort and pain
- Getting conflicting advice from others
- Distrust of providers
- Other issues, such as work schedule or family needs
- Denial that the illness is even present
- Fear of the unknown—or even of the known—effects of following the treatment plan

Helping patients with transitions:

1. Speak with the patient about his or her values. What matters most?
 - Each person has different priorities. Here are a few:
 - A long life
 - A better quality of life
 - Spending more time with loved ones
 - Keeping a job
 - Having a child
2. Frame your communications in terms of how the desired behavior will help support the patient's values and goals.
 - For example, a patient who wants to keep his job may be motivated to choose a home dialysis option for schedule flexibility.

CHAPTER 4. SURVEYS OF PATIENTS, PROVIDERS, AND PRACTITIONERS ABOUT TRANSITIONS OF CARE

Surveys of Patients, Providers, and Practitioners about Transitions of Care

In 2013 and 2014, we surveyed patients, practitioners, and dialysis staff about what transitions they thought were difficult or challenging. The surveys were limited because they went to a relatively small number of persons compared to the large number of patients who are on dialysis and the number of practitioners and dialysis staff members across the country. However, they still provided valuable information useable by dialysis staff and practitioners. We used what we learned to create the chapters of this toolkit.

The transitions included in the surveys were:

- The first dialysis treatment
- A hospital admission
- A hospital discharge
- Change in dialysis type (modality)
- Beginning dialysis
- Resuming dialysis following a failed transplant
- Having new clinic staff
- The transition from pediatric to adult ESRD care
- Travel
- Transitions between the dialysis clinic and skilled nursing facilities
- Changing dialysis units

This toolkit focuses on transitions that patients, practitioners, and provider staff considered most challenging or potentially unsafe.

Results

Patients, practitioners, and providers were all concerned about the frequent lack of preparation of patients for RRT. There were some differences in what they considered good preparation for dialysis. For many transitions of care, patients generally had different concerns than those of dialysis staff and practitioners.

In brief, patients were most concerned about:

- Lack of preparation for kidney failure
 - This included not knowing RRT options or what to expect in the short and long terms. They did not know how being a dialysis patient would affect their identities, employment, social relationships, and standings in society.
- New or inattentive staff
- Any change in dialysis staff

- Changing treatment type or setting
- Getting mixed messages and instructions about medical information from different practitioners and providers
- Hospital staff who do not understand needs of kidney patients
- Hospital staff who do not know how to use dialysis equipment, such as different peritoneal dialysis devices
- Changing dialysis facilities
- Fear of retribution if they complained

Practitioners were more focused on:

- Difficult communications with outside providers
- Lack of timely or complete records from other settings, particularly hospitals
- Hospitalizations that occur without nephrologist knowledge
- Poor coordination with outside providers, including hospital discharge planners
- Coordination with SNFs and other care settings
- Inadequate hospital discharge planning and premature discharges
- Medication reconciliation
- Pediatric to adult transitions
- New dialysis staff
- High patient to staff ratios particularly when there are new staff members

The concerns of dialysis staff were similar to those of the practitioners. They especially focused on the lack of communication about discharge plans from hospitals and poor coordination with SNFs and LTACs. In addition, they often reported:

- Inadequate new patient education, particularly if patients were given bad information in the hospital or were not hospitalized for their first dialysis treatments
- Not enough staff, particularly when there are new, less experienced staff members
- Difficult patient transition from CKD to dialysis
- Premature hospital discharge, particularly of very ill patients
- Poor hospital discharge planning
- Changes in clinic ownership, new policies, and new EMRs that distract from patient care

These lists do not include all the concerns that were reported and not everyone had the same complaints. They do tell us that there are different challenges for patients than there are for dialysis staff and practitioners.

Take Home Messages:

1. Patients, practitioners, and dialysis staff have different perceptions and concerns about transitions of care.
2. Dialysis teams need to understand what transitions are important to patients.
3. At the same time, the dialysis team needs to ensure safe transitions between institutions and even between different dialysis team members.

CHAPTER 5. THE TRANSITION TO DIALYSIS: THE FIRST DIALYSIS TREATMENTS

Problem: Patients do not know what to expect when they start dialysis. Starting dialysis is frightening.

Goal: Help patients know what to expect at the first dialysis treatment and in the near future. Help patients learn their options, how to make their needs known, and how to engage in their own care.

Part 1: Introduction

Starting dialysis is a major life change for patients. What seems to be a smooth transition from the provider perspective may be frightening and confusing for patients.

Most patients who responded to our surveys found starting dialysis to be challenging and even unsafe. Even patients who had education about their options before they started treatment did not know what the experience of dialysis would be like. They often found that no one told them what was happening at each step of the way during the treatment. Most of the information (pamphlets, websites, etc.) provided to patients tries to make the idea of dialysis less scary and to tell them that they can still have almost normal lives. However, it does not tell them what to expect when they walk through the door of the clinic and sit in that chair for the first time.

There are steps that can be followed in the dialysis clinic that can make patients feel safer and encourage them to engage more fully in their own care.

Part 2: Get Started

Gather the team. What problem is most urgent, and which is the greatest concern for patient safety? Decide how you want to define the problem. Start asking “why” it occurs. List the causes and the causes of the causes—and keep asking why. Then consider solutions. Solutions must be things over which you have control and that will improve the outcome.

Turn good solutions into **processes** that can be “hardwired” into the working of the clinic. Solutions should not have to be re-invented every time the problem arises.

Dialysis clinics already have processes in place to ensure safe patient care. They can also create processes for improving the patient transition experience when dialysis begins. Examples might include assigning a “mentor” to each new patient or routinely scheduling a meeting with each new patient and/or family to address questions or fears about dialysis.

*Here is a **sample** list of what patients report about how difficult the transition to dialysis can be, simplified to keep it brief. The boxes in the left column contain actual patient comments. The right column lists potential solutions, also simplified. Adapt this for your clinic. Write a list of causes and solutions based on situations, patient mixes, and resources. Ask patients how they felt and what it was like starting treatment in your clinic. That will help guide the plans.*

What Patients Say	Causes	Solutions
<p>“Am I going to die?”</p>	<p>Why is starting dialysis so difficult and challenging for patients?</p> <p><i>(Note that the causes and possible solutions shown here do not line up. It will be your job to line up causes and solutions for your own clinic.)</i></p>	<p>What can we do now and in the future to make the transition less frightening and overwhelming?</p> <p>Use each section to help design a quality improvement project.</p>

What Patients Say	Causes	Solutions
<p>“Fear can take on either of two forms when it gets ahold of you. You can EXTERNALIZE it, and it can come out as hostility, aggression, or just plain bitchiness. Or you can INTERNALIZE it where you will hold it in and panic quietly to yourself. It is easy to spot externalized fear, but it is not so easy to see internalized fear unless you are looking for it. And BOTH forms of fear shut down your ability to process information.”</p>	<p>1. Fear</p> <ul style="list-style-type: none"> • Kidney failure is a frightening, life changing diagnosis. • The patient is likely fearful of the treatment, of the future, and of the unknown, regardless of his or her appearance. • Fear may be masked as anger, withdrawal, denial, or even a happy face. Patients cannot learn when they are afraid. 	<ul style="list-style-type: none"> • Do not minimize the feeling of fear; acknowledge it. • Talk and touch (as appropriate for the patient). A hand on a shoulder or arm can be very soothing. • Point out that the patient is in a tunnel, not a cave. Start looking for the next step in the patient’s RRT “career.” Provide patient success stories. • Set up a patient mentoring program; your ESRD Network can help. There are several resources in the appendix.

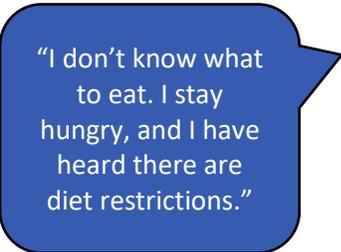
What Patients Say	Causes	Solutions
<p>"I had a hard time transitioning into dialysis and being properly informed about treatment options available."</p>	<p>2. Not knowing treatment options</p> <ul style="list-style-type: none"> • Education about treatment options may not have been done or may have been done at a difficult time. • The patient was too overwhelmed to understand the options. • Options may have been presented in a biased manner. 	<ul style="list-style-type: none"> • Even if it was done pre-dialysis, repeat dialysis options education (if appropriate). Do not present modality options in terms of "pros or cons," since what is a "pro" for one patient may be a "con" for another. • Have a patient who is on a different modality speak with the patient about that modality. A patient who has used more than one modality may be very helpful. Patients often listen more to each other than they do to staff. • Provide written and online educational resources, like www.mydialysischoice.org. • Stress that there are options (if appropriate) and that the patient's choices may change over time. • Discuss all modalities, <u>even those not offered by your clinic</u>. This is a regulatory requirement. There may be another clinic available to the patient that does offer that modality.

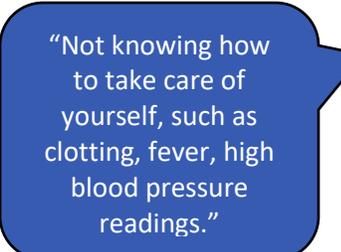
What Patients Say	Causes	Solutions
<p>"Not knowing what I don't know yet."</p> <p>"I passed out because my blood pressure fell too low."</p> <p>"No one explained what they were doing or why."</p> <p>"There was no consideration that this was my first treatment."</p>	<p>3. Not knowing what to expect</p> <ul style="list-style-type: none"> • The patient did not visit a dialysis clinic before starting treatment. • No one took the time to explain each step of before or during the treatment. • The patient has language or other barriers to understanding what has been discussed. • The patient did not want to know anything before starting (denial?). • The patient is very scared. 	<ul style="list-style-type: none"> • Whenever possible, have the patient and/or family visit the clinic and meet with the nurse or other staff before starting treatment. Discuss what will happen at each step starting when the patient enters the clinic. • Have a nurse and/or PCT explain each step of the treatment before, during, and after. If you can, arrange for extra staffing when a new patient starts dialysis. Have a designated "trainer" or at least a standard process for staff to follow. • Include family in the clinic orientation and teaching processes as much as possible, depending on the patient's wishes. • Think about having an orientation area for new patients. You can also ask a current patient to be a buddy for a new patient—speak with him or her

		<p>during treatment, etc.</p> <ul style="list-style-type: none"> • Ask questions so you know if a patient is able to process what you are trying to teach. “Teach back.” • Be patient and sympathetic. <i>Never minimize fears or concerns.</i> • Make sure that the patient and family understand clinic “rules.” Examples include eating on dialysis, visitor policies, whether to bring one’s own blanket, etc. Have a written list of clinic “rules” that you give to the patient and family. • Encourage the patient to speak up about his or her concerns. For example, if he or she sees that someone has not washed his or her hands, say something or place a note in a confidential box meant for feedback. If he or she is afraid to say it to the caregiver, tell them whom they can talk to. • Make sure the patient knows who to speak with if he or she has questions, concerns, fears, or ideas about ways to improve care.
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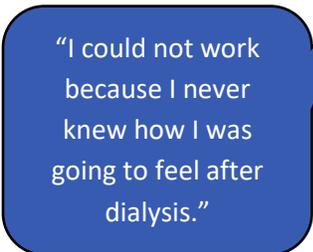
What Patients Say	Causes	Solutions
<p>“...the hospital did everything correctly in preparing my transition of care. They provided print material, handouts, and videos that I could and did watch from my hospital bed. I know that I went through it all—but I remembered little, if anything.”</p>	<p>4. Being given huge amounts of information</p> <ul style="list-style-type: none"> • There are a lot of forms that must be signed, including consents. • <u>Information overload</u> is an issue at the start of dialysis. The information is in a huge bundle that does not prioritize what needs to be done or known urgently and what can wait. • Information was not given pre-dialysis. • Information given by healthcare staff can be hard to understand, especially if it is just 	<ul style="list-style-type: none"> • If possible, have the patient go through the consents and forms <i>before</i> arriving for the first treatment. • If possible, discuss the most urgent information before the patient starts dialysis, whether at the clinic, in the hospital, or at the doctor’s office. <u>Repeat</u> it again soon. If possible, have the inpatient nurses review it with the patient. Some of the critical information includes dietary instructions and how to care for an access. • Put the most urgent written pieces (e.g., safety, potassium, what to do if you have a fever, catheter care) in a small bundle for review right away. Discuss these items with the patient and family very soon.

	<p>verbal or stated just once.</p>	<ul style="list-style-type: none"> • Send selected educational materials and information to the nephrologist’s office or the hospital. Ask them to give it to the patient <u>before</u> the first outpatient treatment. • When you provide education, ask the patient questions to find out if he or she understands the information. “Teach back.” • Timing is key. Tailor the timing of non-urgent content based on the patient’s comprehension and reaction to starting dialysis. • Consider using a volunteer “patient mentor” to help the patient sort through the piles of information.
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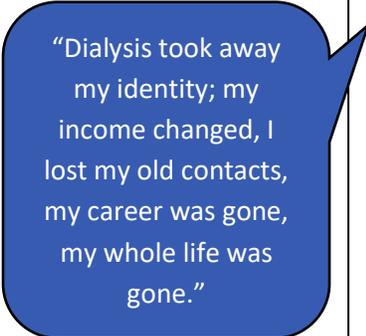
What Patients Say	Causes	Solutions
 <p>“I don’t know what to eat. I stay hungry, and I have heard there are diet restrictions.”</p>	<p>5. Not knowing about diet or fluid consumption</p> <ul style="list-style-type: none"> • There was no pre-dialysis nutritional education. • There was no individualized education when the patient started dialysis. • Faulty information was given by well-meaning friends and family or even non-dialysis healthcare providers. 	<ul style="list-style-type: none"> • Discuss the patient’s individual needs with the nephrologist or advanced practitioner when the patient starts dialysis. Ask what, if any, fluid or dietary limits or supplements the patient needs when he or she starts treatment. Go over them verbally and in writing with the patient as soon as you can. • Do a standard nutritional evaluation right away even if the dietitian is not immediately available. • Tell the patient (nicely!) that non-dialysis providers and others may not know about the needs of dialysis patients. Urge them to check with a dietitian, nurse, or doctor in the dialysis clinic before acting on outside diet or fluid advice.

What Patients Say	Causes	Solutions
 <p>“Not knowing how to take care of yourself, such as clotting, fever, high blood pressure readings.”</p>	<p>6. Not knowing about what to do between treatments if something goes wrong</p>	<ul style="list-style-type: none"> • Have written materials (at the sixth grade reading level) about what to expect, what is normal, and what needs further assessment. Include when to go straight to the emergency room or urgent care. Make sure that family and other caregivers know what to do.

		<ul style="list-style-type: none"> • Provide a list of important phone numbers of practitioners and providers, including the nephrologist and other nephrology practitioners, the access surgeon, and the dialysis clinic. • Make sure the clinic voice message has instructions about how to call the provider or other personnel (e.g., the home dialysis nurse), provides the fax number of the clinic, and informs them to dial 911 in an emergency. • Think about whether a patient needs extra help (e.g., home health care), even on a short-term basis. Collaboration with home health care can be a huge help.
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What Patients Say	Causes	Solutions
 <p>“I could not work because I never knew how I was going to feel after dialysis.”</p>	<p>7. Worries about finances, transportation, employment, etc.</p> <ul style="list-style-type: none"> • Patients may think they cannot work if they are on dialysis. Sometimes that is not true. • The dialysis schedule may interfere with the patient’s work. • The patient cannot count on feeling well enough to work regularly. • Disability pays very little compared to what a patient earned on a job. • Medications can be very expensive and not well covered with the patient’s health plan. • Public transportation may not be available. Even if it is available, it may not be a good option. 	<ul style="list-style-type: none"> • As soon as possible, ask if the patient and/or family have concerns about finances. Include whether the patient expects to return to work. If not, why not? • If possible, consider home dialysis or a work-friendly schedule so that patients keep their jobs and health plans. • If your clinic cannot help a patient keep a job due to scheduling or other reasons, see if a nearby clinic can. Work with the employer (with patient permission) if accommodations are needed for continued employment. • Ask the patient how he or she feels post-dialysis and on the in-between days. Adjust the dialysis prescription or consider a different treatment modality if it might help. • Not all patients can keep working. The dialysis team is more knowledgeable about the challenges of continued employment for dialysis patients than is the PCP. Help the patient with his or her short- or long-term disability needs. • Be sure the patient can afford his or

		<p>her medicines, transportation, etc. Have the practitioner review expensive medications for affordable alternatives.</p> <ul style="list-style-type: none"> • Unless the clinic can provide transportation, make sure the patient and family know that the dialysis clinic does not provide transportation. Before you take a new patient, make sure that he or she has transportation. Help the patient and family find transportation alternatives if necessary. Consider home treatment if transportation is difficult. • Know what community resources exist for rides, food (e.g., Meals on Wheels), and medication assistance. If possible, give the information to the patient before the first treatment.
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What Patients Say	Causes	Solutions
 <p>“Dialysis took away my identity; my income changed, I lost my old contacts, my career was gone, my whole life was gone.”</p>	<p>8. Patient’s perceived change in identity and social standing</p>	<ul style="list-style-type: none"> • Assess for depression as soon as possible. • Involve the social worker and the family and support system as soon as possible. • Acknowledge patient fears. • Encourage patient engagement in care. Do not take away patient autonomy or ability to take control of his or her own care. • Encourage the patient to remain active in his or her social circles.

CHAPTER 6. DIALYSIS STAFF CHANGES

Problem: Patients may not have a trusting relationship with new staff members and are frightened. Patients often experience loss and grieve for the staff member who has left.

Goal: Ensure that all staff members understand and respect patient anxiety when new or less experienced staff care for them. Provide new staff with skills to address the anxiety. Develop strategies to ensure that staff are thoroughly trained and competent before they work independently with patients. Help patients through the grieving process when a trusted staff person leaves.

Part 1: Introduction

Most patients listed changing staff as a challenging and/or unsafe event. This is true for *any* staff change, including shift change, new staff, changing clinics, changing treatment options, etc. Patients rely on staff for their lives and know that they can have serious complications if dialysis is not performed safely.

Patients are aware of tensions between staff in the dialysis unit, whether a staff person is fully trained or not, and whether a new staff person is being supervised. Access management by new staff is high on the patient list of concerns. They watch to see whether safety procedures are being followed. They also know when there are communication gaps between shifts or if a staff person is unfamiliar with patient needs due to poor communication or lack of trying. A dialysis unit can be compared to a big family with all its good sides and its flaws.

Often overlooked is the sadness that patients feel when a trusted staff member leaves for a different job, retirement, or other reason.

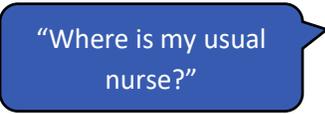
Part 2: Get Started

Gather the team. What problem is most urgent, and what is the greatest concern for patient safety? Decide how you want to define the problem. Start asking “why” it occurs. List the causes and the causes of the causes—and keep asking why. Then consider solutions. Solutions must be things over which you have control that will improve the outcome.

Turn good solutions into **processes** that can be “hardwired” into the working of the clinic. Solutions should not have to be re-invented every time the problem arises.

Dialysis clinics already have many processes in place, such as assigning a specific person to check water quality at designated intervals. The clinic can also create processes for improving the patient transition experience. Examples might include having old and new staff persons meet together with the patient during a staff transition whenever feasible (e.g., the home dialysis and the hemodialysis nurse). At shift change, have the new dialysis staff verbally review communications from the previous dialysis team with the patient (e.g., what the access problems have been).

Here is a **sample** list of what patients report about why it is hard to adapt to new staff, simplified to keep it brief. The boxes in the left column contain actual patient comments. The right column lists potential solutions, also simplified. Create your own list of causes and solutions based on situations, patient mixes, and resources. Ask your patients what their experiences and perceptions have been to guide your plans.

What Patients Say	Causes	Solutions
 <p>"Where is my usual nurse?"</p>	<p>Why is it hard for patients to adapt to new or different staff members?</p> <p><i>(Note that the causes and possible solutions shown here do not line up. It will be your job to line up causes and solutions for your own clinic.)</i></p>	<p>What can we do now and in the future to make the transitions in staffing a better experience for patients?</p>

Author's Note: Access issues are covered first, since access cannulation is a major concern when patients were asked about staffing changes in our surveys. Pain was noted more often than loss of the access.

What Patients Say	Causes	Solutions
 <p>"New techs do not have a good understanding of my access, depth, curves, narrowing, etc., causing the new staff member to fish around the access to cannulate, causing pain and infiltration."</p>	<p>1. Fear of painful cannulation or access damage by new staff</p> <ul style="list-style-type: none"> • There is no common place to share access details, which is especially vital for the patient with a difficult or unusual access. • Orientation for new staff members, especially PCTs, is often too short. • Staff may not have been thoroughly educated about how to assess an access prior to cannulation. • Senior staff do not mentor newer staff. New staff are allowed to cannulate without a 	<ul style="list-style-type: none"> • Make sure there is a section in each patient's chart (or EMR or clipboard) with a detailed access drawing if a fistula or graft is present, with information about cannulation. Require all RNs and PCTs to view the drawing before cannulating if they have not worked with the patient before. • Insist on in-depth staff education that includes access assessment and prolonged mentoring by senior staff. Do not pretend that a new staff person has extensive experience. • Make sure that there is always a PCT or RN with good cannulation skills in the clinic to help other staff who need it. Enforce policies that limit the number of cannulation attempts, and <u>tell</u> patients about those policies. • Staff floating within one company's clinics should have the same skills.

<p>"I have found not all staff members are equal. Even staff who have been there a while may have trouble cannulating me. When the people who know my access are on vacation, I am scared to go to dialysis."</p>	<p>senior person with them.</p> <ul style="list-style-type: none"> • Staff may be asked to work independently too early in their orientation. • PCTs sometimes try to cannulate an access too many times before getting help. • Some staff may not be trained on all access types. • The staff person assigned to a patient may not be good with <i>that patient's</i> access, even if he or she is competent with other accesses. • Staff may not be fully trained for access emergencies. 	<p>They need centralized training.</p> <ul style="list-style-type: none"> • Assign the best PCT or RN to cannulate an access—regardless of the general staff assignments. Whenever feasible, respect a patient’s right to refuse to be cannulated by someone he or she fears will cause pain or access damage. • Teach patients about their own accesses. Patients who are capable of learning should know which side is arterial and which is venous, whether there are spots that should not be cannulated, where the needles should be placed for good site rotation, etc. Mentor new staff. • Respect the information that the patient provides about the access. • Teach staff and patients what to do in case of an access emergency, like needle dislodgment.
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What Patients Say	Causes	Solutions
<p>"New staff is like starting dialysis all over again and feeling the loss of a trusted friend when an experienced staff member leaves."</p>	<p>2. Patients bond with their caregivers. They may not trust a new staff person or healthcare team. When a trusted staff member leaves, they feel the loss.</p> <ul style="list-style-type: none"> • Patients do not know if a new staff person is experienced or good at his or her assigned job. • They are afraid that the new team or person does not know or respect their needs. • Novice staff, including RNs and PCTs, may not be given enough orientation or training for the responsibility they take on when caring for complex patients and a difficult therapy. 	<ul style="list-style-type: none"> • Greet all patients and visitors as they enter the unit (by name, if possible). • Make sure all staff introduce themselves to new patients and tell the patient what their position is in the unit. • New staff members should introduce themselves to patients. • Teach staff how to ask open-ended questions while providing care to encourage patients to explain their thoughts. • Assign a mentor for each new staff member for long-term support—up to a year. • Do not shorten orientation for new staff who may be experienced in other aspects of medicine, but not in dialysis. • Make sure that there is a senior staff person present at all times to

<p>“New staff that do not know you or read the chart and do not set the machine up right.”</p> <p>“Not enough time to say good-bye or to discuss the grief and loss of a trusted staff person.”</p>	<ul style="list-style-type: none"> • A nurse’s education and experience in areas other than dialysis does not mean that he or she will succeed in dialysis. • Patients are afraid of complications and do not know if a new staff person can handle emergencies. • Patients are afraid of retaliation if they complain. • Patients may miss a trusted staff person who has left and have a hard time trusting a new person. 	<p>handle complex problems and emergencies.</p> <ul style="list-style-type: none"> • Do not pretend to be an expert on everything; be open about asking for help when needed. • Do not minimize patient fears. Acknowledge them and discuss them. • Make sure it is clear that someone is always watching patients (not surfing the web) and that there is always back-up. • Require that a staff person assigned to patient care has a backup person when he or she leaves the treatment floor. Make sure each patient knows the identity of the back-up person. • Have a confidential process for patients to share their fears and concerns about the unit or any staff, such as a suggestion box. Make sure that the process ensures that there is no retaliation when a patient complains. • Patients should know who to go to with concerns. This may be a social worker, administrator, or other person. • Teach patient/provider conflict resolution techniques to new staff members. (ESRD Networks can help. The full workbook on decreasing patient/provider conflict is available online at http://esrdnetworks.org/special-projects/dpc_provider_manual.pdf.) • Have a team that includes patients develop a mentoring program for new patients and new staff. • Know that patients may miss another staff person; do not take this personally. Listen to patients and empathize when they discuss loss of a staff person.
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What Patients Say	Causes	Solutions
<p data-bbox="191 235 492 982"> “Staff turnover is the most challenging. With every change, there is the potential for miscommunication or lack of communication. If the patient does not speak up, they may not be aware that the technicians are not working with the same set of instructions.” </p> <p data-bbox="191 1333 492 1717"> “New staff that do not know you or read the chart and do not set the machine up right.” </p>	<p data-bbox="524 235 932 478"> 3. Poor communication between care teams, team members, and patients can apply to shift change, changing dialysis days, changing dialysis clinics, or having new staff. </p> <ul data-bbox="524 487 932 1522" style="list-style-type: none"> • No “report” with each hand-off of patient care (e.g., shift change). The short turnover time between patient treatments may not allow for thorough communication. • What hand-off communication there is does not include patient input. • Dialysis is a routine procedure, so it is possible for assumptions to be made or details missed. • Dialysis is routine for the staff, and they may overlook that it may not seem routine to a patient. • Notes about a patient’s unique needs are not available to the staff caring for him or her. This could include items such as orders not to use clamps or the need for a sitter. • Staff do not communicate to the patient what they are doing with the machine or what medications they are giving. 	<ul data-bbox="964 235 1419 1875" style="list-style-type: none"> • Schedule overlap shift time for staff to receive reports before caring for patients. • Standardize a communication plan for hand-off of care with each transition. This may require a checklist even for shift changes. • Make the treatment orders and plan readily available for all patient care staff. In addition to the dialysis prescription, it should include issues that are unique to that patient, such as, “highly fearful of needles.” It may include short term plans, such as the date a fistula should be cannulated for the first time. (A treatment plan is not the same as the patient care plan, which is a much more extensive document.) • Expect all staff to review the treatment orders and plan before caring for a patient. Always tell a patient what you are going to do before you do it and explain why it is important. • Insist on a “no tolerance” environment for harassment between staff and between patients and staff. This includes one staff person speaking badly about another. This is different than expressing that there may be valid differences of opinion. Concerns about staff competence should be discussed with a supervisor in a private location. • Have a climate where patients and staff work together to improve care. Staff can role model reminding each other to complete hand hygiene and can ask patients to remind them. The key is for staff to kindly accept the feedback. • The clinic can consider

		<p>participating in formal teamwork training, such as the TeamSTEPPS program that is used in many hospital settings. Many organizations offer teamwork training in their continuing education programs.</p> <ul style="list-style-type: none"> • Have patients and staff on a committee together. An example would be an infection control committee that sets a goal of 100% hand washing and clean gloves before cannulation. • Inform patients and staff before changes in policies or personnel go into effect. • Allow time and a process for dialysis staff and patients to share their concerns and fears in a safe and confidential way. This may include sharing concerns only with the administrator, always in a private space outside the treatment area.
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What Patients Say	Causes	Solutions
<p>“High turnover of technicians means a high learning curve and more new staff.”</p> <p>“You as a patient are an unknown. The issue of safety comes into play. Are you making a complaint as a complainer or do you really have a need? When I ask for a blood pressure check, it is because I may be within 5 minutes of a major drop, not because I want attention. To a burned out dialysis nurse, I may appear to be an annoyance, but if I do not get that check quickly, I will be an emergency about to pass out.”</p>	<p>4. Dialysis staff may be “burned out.” Turnover is high in some units.</p> <ul style="list-style-type: none"> • Causes of turnover vary. Some common perceptions are: <ul style="list-style-type: none"> ➢ Unsupportive leadership ➢ Poor pay ➢ Long hours ➢ Understaffing ➢ Difficult, complex patients ➢ Not knowing enough about the job before taking it ➢ Lack of employee input into decision making 	<ul style="list-style-type: none"> • Make sure the right person is hired for the right job. Administrators should “weed out” employees with poor attitudes or work ethics, as they affect everyone negatively. • Make sure training is thorough and long enough for staff to feel comfortable with their duties. • Create a safe haven for staff where leadership listens to concerns and uses a “just culture” algorithm so staff want to stay at a clinic. Do not punish staff for human error. There is an old adage that people will work in bad situations if the leadership cares and shows it. • Have a “go-to” person as a resource for new staff. • Teach de-escalation techniques early in orientation (Verbal Crisis Prevention). • Ask patients why they believe a staff member left and get their opinions of the culture in the clinic. • Consider an anonymous survey about what patients see as strengths and weaknesses or problems in the clinic. • Leadership should be highly visible to both staff and patients.

What Patients Say	Causes	Solutions
<p>“I am afraid of retaliation if I complain.”</p>	<p>5. Sometimes staff does not follow safety procedures, especially for infection control. It is difficult to speak up to a new and unfamiliar staff person. New staff also do not always know what to do in case of an emergency.</p> <ul style="list-style-type: none"> • Safety and infection control procedures may not be monitored or enforced. • Fearful patients may be very 	<ul style="list-style-type: none"> • Empower staff to monitor and help each other to follow policies and create a safe environment. Teach patients and staff the same information on infection control. • Teach emergency steps in patient care to all staff, including what to do for bleeding, passing out, blood pressure drops, etc. • Have a plan for other emergencies such as tornados, ice storms, and water outages. Teach this plan to both patients and staff regularly.

	<p>suspicious of staff actions, especially if a procedure is new or different.</p> <ul style="list-style-type: none"> • Fear of retaliation for speaking up is real. • Patients may feel that no one will listen. • Patients may not have enough information on emergency or infection control procedures. 	<ul style="list-style-type: none"> • Post the clinic’s infection goals with strategies for improvement on which both patients and staff are working. Post the progress on improvement where both staff and patients can view it (e.g., the percentage of patients who wash their access before dialysis). (Infection rates can be posted as percentages. No patient identifiers please!) • Have a confidential way for patients to report concerns and monitor for any behavior that may suggest retaliation.
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What Patients Say	Causes	Solutions
<div data-bbox="201 852 493 1388" style="border: 1px solid black; border-radius: 15px; padding: 10px; background-color: #4a7ebb; color: white;"> <p>“Conflicting information given to a patient by different staff members leaves the patient confused and scared, ending up with less trust of dialysis staff.”</p> </div>	<p>6. There may be mixed messages between staff and between the practitioners and the staff.</p> <ul style="list-style-type: none"> • Different staff may give differing answers to patient questions. • Patients hear advice and opinions from many persons (primary care providers, emergency room personnel, friends, and family) outside of the dialysis clinic that may conflict with what they hear in the clinic. 	<ul style="list-style-type: none"> • Staff should be thoroughly oriented on questions patients often ask. • Identify and develop a “go-to” person from whom less senior staff can get answers. • Ask patients if they are getting the answers they need or if they want to know more. • Ask patients how they prefer to learn. If they want print materials, be sure they are accurate, up to date, and written at a sixth grade reading level. • Involve the person with the most expertise. For example, an RN or PCT may know enough about nutrition to answer basic questions. Tell the dietitian that the patient wants to know more. Have patients ask the practitioner when they have questions about the dialysis prescription. • Do not speak badly of the person outside the clinic who gave poor advice! Correct the error tactfully. For example, you might say that dialysis and kidney failure create medical needs that are unique and not many people know about them. What is good for most people may not be good for someone on dialysis.

CHAPTER 7. MODALITY CHANGES

Problem: Changing treatment modalities can be difficult. Patients are often insecure about making the change.

Goal: Help patients understand what to expect when changing modalities. They need to know how and who to ask for help and how to be engaged in the process.

Part 1: Introduction

Transitions between modalities include the change from in-center dialysis to home dialysis, change to a different type of dialysis, or even change from daytime to nocturnal dialysis. It also includes stopping dialysis following a successful transplant or starting dialysis after a failed transplant. For some patients, it includes stopping dialysis and starting supportive care. Supportive care is often hospice care, but not always. Some changes are voluntary, such as when a hemodialysis patient wishes to try peritoneal dialysis. Often the transition is involuntary, such as when a transplant fails. In our surveys, most patients reported that a modality change is challenging and/or a safety threat. This was especially true for the transition from transplant to dialysis. Most providers also found modality changes to be challenging, but not a threat to patient safety.

Some patients compared changing modalities to starting over on dialysis. Many spoke of the challenges of having new care teams. Many of the causes and solutions are like those of starting dialysis and of changes in care teams. Both of these topics are covered in other chapters of this toolkit, so please read those chapters, too.

Change in general can be a challenge. However, there is little information about why kidney patients find changing modalities to be a challenge or a safety risk. One study found that patients on any type of dialysis were reluctant to change, even if the new modality would help them live longer. Another study found that many patients did not pursue transplant because they felt they were doing well enough on dialysis. Nevertheless, change does happen, and providers need to know about the concerns of their patients.

Modality changes can involve “systems” challenges, as well as personal ones for the patient. A system challenge could be that a patient’s health plan will only pay for a certain transplant center that is hundreds of miles from home. Another problem may be that a patient does not have enough space at home for the machine and supplies for PD or HHD. Include system issues when you look at barriers to change. Some of them are not under the control of the dialysis clinic, though at times clinics and/or patients have found solutions. An example of a personal challenge would be the patient’s fear of failing to perform peritoneal dialysis safely.

The bulk of this chapter discusses changes in dialysis modalities and the transitions between transplant and dialysis. We briefly address the transition to supportive, non-dialysis care. This final transition has profound effects on both patients and providers. Supportive care is not renal replacement therapy.

However, the transition to supportive care is an important part of the continuum of care that occurs in the dialysis setting.

Hospice care is one form of supportive care. With hospice care, the caregivers expect the patient to pass away and the intention of treatment is to keep the patient comfortable. Sometimes patients have enough kidney function to keep them alive as long as they receive medications and other treatments that will control fluid build-up and other symptoms, but they are not on RRT. Some of these patients resume RRT later, and some eventually receive hospice care.

Part 2: Get started

Gather the team. What problem is most urgent, and what is the greatest concern for patient safety? Decide how to define the problem. Start asking “why” it occurs. List the causes and the causes of the causes—and keep asking why. Then consider solutions. Solutions must be things over which you have control that will improve the outcome.

Turn good solutions into **processes** that can be “hardwired” into the working of the clinic. Solutions should not have to be re-invented every time the problem arises.

Clinics already have many processes in place to ensure safe patient care. The clinic can also create processes to improve patient changes between treatment modalities. An example may be to have a nurse, social worker, or practitioner sit down with the patient and family and formally assess what they see as advantages and disadvantages of a new modality. This could help the team foresee future challenges. You can also have a peer mentor program so a patient who is new to a modality has a source of support (but not medical advice).

*Below are **sample** lists of what patients and providers/practitioners report about the difficulty of the changing modalities, very simplified. We have also included the “systems” barriers that occur, but were not included in the comments received in our surveys. Next to them are samples of causes and potential solutions. Use these or add your own. Ask your patients how they felt and what changing a modality was like. That could help guide your plans.*

There are four major sections of samples. The first addresses concerns expressed by patients. The second is largely a list of concerns associated with specific modality changes. Providers and practitioners should be aware that these concerns may be barriers to change and be prepared to address them. The third section is about the transition from RRT treatment to supportive care. The fourth section is about practitioner and provider concerns when a patient transitions from transplantation to dialysis. This section highlights the need for collaboration between the nephrology practitioner, the transplant team, and the dialysis team.

Section 1: General Concerns

What Patients Say	Causes	Solutions
<p>“It is always difficult going from one treatment to another. The unknown is kinda scary!!!”</p>	<p>Why is it challenging or even potentially unsafe to change RRT modalities?</p> <p><i>(Note that the causes and possible solutions shown here do not line up. It will be your job to line up causes and solutions for your own clinic.)</i></p>	<p>What can we do to make ESRD modality transitions more “user-friendly” for patients?</p>

What Patients Say	Causes	Solutions
<p>“Success with a chronic illness is a very delicate balance. Any change can interrupt a patient’s health in a major way that may or may not be correctable. If the change produces an irreversible side effect, the patient may deal with that consequence the rest of his or her life. Over the decades, I have been very resilient. As I age, compounded with dialysis, my resilience has dramatically worn down. My social and family networks of support have also worn down.”</p>	<p>1. Change in general is hard. There is always the possibility that things will go wrong.</p> <ul style="list-style-type: none"> • Patients fear that the change will not be better. • Fear causes resistance. • Patients fear losing control. Familiar routines help them feel in control. • There may be a lack of family or social support for treatment changes. • Patients fear that they will fail, particularly if going to a home modality. • It may be hard to get “back on track” if things do go wrong (e.g., poor nutrition, infections, transplant rejection). <p>“Changing from dialysis to transplant due to changes in diet, activity, and lab changes.”</p>	<ul style="list-style-type: none"> • Acknowledge that things can go wrong. • Offer the positive aspects of the change (e.g., more independence, feeling better, less infection risk—depending on the modality). • Have the patient speak with at least one other patient who is on the modality he or she is considering. • Find out if there are specific worries that the patient can state. Examples might be the needle sticks on hemodialysis or the fear that no one will be there to help with PD in the middle of the night. <u>Do not minimize those concerns.</u> Address them. • If possible, do not rush the change. As much as possible, keep the patient in control over modality choice and timing. This may not be an option when a transplant fails abruptly or a patient has severe peritonitis. • Get the patients to focus on where they want to be in the future. Remind them that they can either focus on hardship or

<p>“I am waiting for a transplant, and I am worried about stories I hear about missing medications or getting the wrong medications... I always say that the patient HAS to play a big (HUGE) role in keeping themselves all in order medically with the transitions from hospital to dialysis to hospital when one is a transplant recipient. What needs to be in place in case the patient is unable to keep things in order? That needs to be addressed.”</p>		<p>imagine success and rewards.</p> <ul style="list-style-type: none"> • Enlist the help of the patient’s support systems, but be careful that they do not pressure the patient. • Make sure that patients know what will happen if things do go wrong. For example, if a transplant does not work, a patient can resume dialysis and can be helped to prepare for another transplant.
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What Patients Say	Causes	Solutions
<p>“Not knowing what to expect, what will be different, what are the processes.”</p> <p>“After years on in-center dialysis, I decided to dialyze at home. This is a huge transition. The first hurdle has been to have me self-cannulate at my regular in-center treatments. No problem at all sticking myself with the telephone pole-sized needles into my excellent fistula. I find myself wondering what my new life will be like and trying to figure out what questions to ask. It feels just like when I started dialysis all those years ago. I just do not know what I do not know yet. A good analogy would be as if I’m standing in line at the big scary roller coaster and moving closer and closer to the front of the line. I know I’m going to have fun, but in the back of my mind, I’m hoping all goes well.”</p>	<p>2. Not knowing what will be new and different from the last treatment type. Sometimes there is fear of both the unknown and the known.</p> <ul style="list-style-type: none"> • Changing a modality is often like starting over with the first dialysis. • Patients may lack information or may have wrong information. 	<ul style="list-style-type: none"> • Treat modality change as a fresh start with dialysis. Even if a patient has been on that modality in the past, there may be changes in the treatment procedures and equipment that are new. • Present modality options education even if it was done before. Do not present options as “pros” and “cons.” Each patient will have his or her own priorities and values that will influence the choice of RRT. What is a “pro” to one person may be a “con” to another. You may have to dig a little to find out what is important to the patient. • Be sure the change is for the patient’s benefit rather than to meet the goals of the clinic. • Explain <i>all</i> of the steps before a patient actually changes the modality. Make sure the patient and family know what will be different including the inconveniences. Examples may include having to keep the cat out of the bedroom at night for a CCPD patient or having to

<p>“Not having enough information about what to expect when changing modalities, what the processes and procedures will be, what will be different.”</p> <p>“The transition that was the most challenging was when I first started peritoneal dialysis, not enough was explained before that type of dialysis was suggested. I needed to know more about the risks.”</p>	<p>add plumbing for HHD.</p> <ul style="list-style-type: none"> • Have the patient speak with another patient who is on the new modality. • If you can, take it stepwise. For example, start teaching about the machine settings while the patient is in-center, before he or she starts formal HHD training. Start with the simple things first.
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What Patients Say	Causes	Solutions
<p>“Changing shifts, (first, second, third, nocturnal).”</p> <p>“Going from transplant to hemo or PD... You lose your support and relationships you have had with your transplant team abruptly and have to start with a new care team, building trust, communication, etc.”</p> <p>“Transitions between any two entities can be risky, mainly because the information that needs to be transferred is not always. I would say it is hardly ever efficiently done, leaving the next team to guess what is needed for that patient.”</p>	<p>3. Changing providers (dialysis staff, transplant staff), practitioners, and even schedules can be hard; new staff and fellow patients are often “unknowns.”</p> <ul style="list-style-type: none"> • The patient may have to change modality, staff, schedule, and often the site of treatment. This is a lot of change. • The patient may not know if new staff will know about his or her history and medical needs or will listen to his or her concerns. 	<ul style="list-style-type: none"> • Introduce new staff and review the patient’s concerns with him or her. • If you are the new provider or practitioner, meet with the patient before the transition. • Make sure there is communication between new and “old” providers and practitioners. Speak with the last team to get specifics that may not be in either paper or electronic records. • Do not accept a patient into a new modality unless you have enough information to ensure a smooth, safe transition. • If you are the new provider or practitioner and do not feel the patient is appropriate for the new modality, speak with the last provider team and discuss it further with the patient. • Do not rely solely on patients to convey information between providers. Keep the patient “in the loop.”

What Patients Say	Causes	Solutions
<p>“I felt a sense of loss for the gift I was given.”</p>	<p>4. Patients who lose a transplanted kidney grieve for the loss of the transplant. This is particularly true if it was from a living donor.</p>	<ul style="list-style-type: none"> • Acknowledge and discuss the loss that the patient has had. • Involve the social worker as soon as possible. Seek outside counseling if the patient needs

	<ul style="list-style-type: none"> • Transplant loss may occur acutely. The patient may not have time to prepare psychologically or physically for dialysis. • Patients may feel very badly about losing the gift they received from the donor. 	<p>it.</p> <ul style="list-style-type: none"> • If the patient has a good relationship with the transplant social worker, ask him or her to meet with the patient.
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What Patients Say	Causes	Solutions
<p>“I was not prepared for returning to dialysis when my transplant failed.”</p> <p>“Transplant back to dialysis: You are dropped like a hot rock from the transplant care team. Expected to jump right back into dialysis... My depression and grieving was not addressed by the transplant care team or new dialysis care team... There also seems to be no specific process at the clinic either, like they have for new patients.”</p> <p>“There are few mental health professionals who specialize in or are trained to deal with chronic illness (ESRD). I think it is a big factor that is overlooked when we have to start or change modalities.”</p> <p>“Travel; changed from transplant to PD to Hemo; on hemo having to find a clinic to dialyze at our travel location; on PD having supplies shipped and stored and carrying equipment on a plane.”</p>	<p>5. Patients have often not been prepared for the change in treatment modalities.</p> <ul style="list-style-type: none"> • The patient may not have a choice in changing modalities (e.g., peritoneal membrane failure or transplant failure). • He or she may not have been told or did not hear that change may be needed in the future. <p>Some patients think that once they start dialysis, they will not be “allowed” to stop.</p> <ul style="list-style-type: none"> • Counseling services for persons with complex medical conditions are scarce. • There are advantages and disadvantages with each modality. The values and priorities of the individual drive the preference of one modality over another. Changing to a modality that may not fit one’s priorities can be difficult. 	<ul style="list-style-type: none"> • Whenever reviewing RRT options, tell patients that they have the option to change modalities in the future <u>and</u> that sometimes they may <u>have</u> to change. • If the modality change is involuntary, acknowledge that change may not be what the patient wants. Discuss how the patient can maintain control. • Address the grief that the patient may have about not being able to continue the modality he or she was on before the change. • Engage the social worker to help evaluate and counsel the patient. Seek outside counseling services if needed. Involve the support services (e.g. transplant social worker or home dialysis RN) from the previous treatment setting. • Supportive care should be included in the review of options. • Make access planning and education a part of the patient’s plan of care, particularly if a change from PD to HD is anticipated, e.g., due to membrane failure, loss of support at home, etc.

What Patients Say	Causes	Solutions
<p>“My feelings towards him are changing, and I sometimes resent having to spend so much of my time and energy taking care of him. Anger towards me is the worst part of dealing with this illness. I am trying to understand, but I am in a state of shock and losing my empathy.”</p>	<p>6. For patients who transition to home modalities, particularly HHD, the caregivers may have concerns or even anger.</p> <ul style="list-style-type: none"> • Turning a spouse or other care partner into a dialysis technician can stress a family. Doing dialysis can become a second (unpaid) job. 	<ul style="list-style-type: none"> • Include the concerns of the caregiver in the decision to transition to a home treatment. • Involve the social worker. • Find out if intermittent respite care is available and if the patient will accept it. The respite may consist of periodically going to in-center treatments for several treatments. • Avoid care partner burnout. Train the patient to be as independent as he or she can be with the treatment.

What Patients Say	Causes	Solutions
	<p>7. Some patients may feel that a modality change is being pushed or not advised for the clinic’s financial gain rather than for the patient’s benefit. This may especially apply to clinics that do not offer all of the dialysis modalities.</p>	<ul style="list-style-type: none"> • Medicare rules and medical ethics require that patients be educated about all options, including those that the clinic does not offer. This may mean a transfer to a competitor clinic.

Section 2: Concerns about Specific Modality Transitions

The challenges that patients face often depend on the specific modality change.

The challenges listed here are largely for informational purposes. They may be on the minds of your patients, even if they do not express them. Ask patients if these are worries they have and talk about them. If a transition is involuntary, the patient may be depressed or angry about any new modality. Some of these are “systems” issues, such as the barriers of space at home for dialysis supplies.

- Transplant to dialysis
 - Loss of control and independence
 - Need for a regimented schedule
 - Adverse impact on work life and choices

- Frailty due to transplant rejection or infections
- Changes in the care team
- Concerns about loyalty to the transplant team
- Worries about not feeling well on dialysis
- Poor dialysis due to poor access
- Medication changes

- Dialysis to transplant
 - Care team changes
 - Complex medication routine
 - Side effects of medications
 - Cost of medications when Medicare no longer covers them or if the health plan does not pay for new or costly medications
 - Health plan requirements to use “Centers of Excellence” for transplant, which may be hundreds of miles from home
 - Costs not covered by a health plan if the transplant center is far from home (e.g., spouse’s lost wages, child- or eldercare)
 - Patient and/or family fear going to an unfamiliar transplant center that is far from home and may just refuse
 - Changes in diet, fluid, etc. (Remember any change is “kinda scary”)
 - Body changes, such as weight gain
 - Concern about loss of the kidney
 - Guilt if the transplant is from a live donor
 - Change in family dynamics, especially if a family member or friend is the donor
 - Increased expectations for work, family life, etc.

- In-center to home dialysis treatments
 - Less contact with the care team
 - New care team
 - Possibly different practitioner
 - Possibly different dialysis center
 - Fear of not being able to reach a nurse or doctor when necessary
 - Family help and support may not be as strong as needed
 - Concerns about doing a treatment by one’s self, including medications
 - Pets and how to keep them out of the treatment room
 - How to set up the room, where to put supplies, etc.

- Specific PD considerations
 - Need for daily dialysis versus three times per week
 - PD catheter concerns, including body image

- Fear of peritonitis, which often stems from advice of medical staff within either the dialysis clinic or elsewhere
- Travel changes, including getting the machine and supplies through the airport

- Specific HHD considerations
 - Need for a care partner
 - Home may not be owned
 - Water procurement or water treatment issues for some patients (often depends on geography)
 - Impact on the family
 - Safety concerns, including those related to vascular access

- Home dialysis to in-center HD
 - Clinical changes, including diet, fluid, possible need for a new access, scheduling, transportation needs, etc.
 - Changes in care team
 - Loss of independence
 - Less “hands on” involvement in treatments
 - Travel is more complex
 - If nocturnal HD:
 - Concerns about being able to sleep during treatment
 - Transportation issues, including driving at night
 - Impact on the family due to being away three nights weekly
 - May see the doctor less often

Section 3: Transition to Supportive Care

<p>What are the barriers to supportive care?</p> <p><i>(Note that the causes and possible solutions shown here do not line up. It will be your job to line up causes and solutions for your own clinic.)</i></p>	<p>What can we do to make the transition from RRT to supportive care more “user-friendly” for patients?</p>
<p>Some dialysis staff and practitioners may not support or understand the transition to supportive care. Patients may not know that it is an option.</p> <p><i>(Note that this topic was not a part of the surveys that were done to prepare for this toolkit, but the authors feel that it is an important, often overlooked, transition of care.)</i></p> <ul style="list-style-type: none"> • Providers do dialysis. Other than the social worker, the staff may have little or no training about supportive care. 	<ul style="list-style-type: none"> • Patients, dialysis staff, and practitioners should know that supportive care is a treatment option for patients, even if the patient chose dialysis in the past. • Review the resources available for patients and professionals about supportive care for dialysis patients. See the Coalition for Supportive Care of Kidney Patients at http://kidneysupportivecare.org. There is a training program for the care team. It also has advance care planning and information for

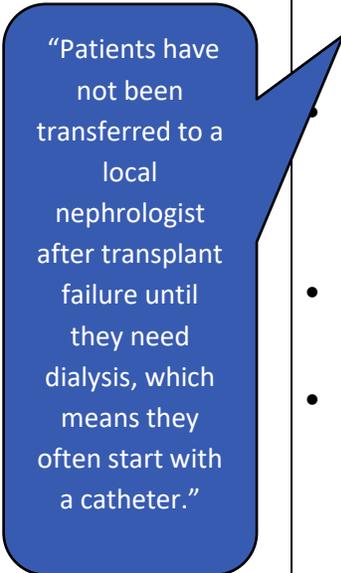
<ul style="list-style-type: none"> • Supportive care does not always mean that the patient enters hospice care. Some patients have enough kidney function to maintain life if they have adequate medical and family support. • Staff and practitioners may be very personally uncomfortable about stopping a life-saving treatment. • Practitioners and staff may be reluctant to stop RRT out of fear that the patient made the choice based on factors that may be reversible with the right treatment, especially depression. • Some providers and patients have religious objections to stopping RRT. • Families may not support a patient’s choice to stop dialysis. • At times, family members may receive financial benefit (e.g., Social Security or disability benefits) that will stop when the patient dies. 	<p>patients and families about supportive care.</p> <ul style="list-style-type: none"> • Patients with active mental illness, including depression, should have their decision-making capacity evaluated carefully. Do not presume they are unable to make treatment choices. The help of a mental health professional may be needed. • If there is an ethics committee available, ask them to meet with the patient, family, and dialysis care team. The committee does not make decisions for the patient, but may be able to help the parties with making decisions. • Ultimately, the decision to discontinue RRT belongs to the patient. The care team should help the patient find resources outside the clinic, including palliative or hospice care services. • If the patient desires palliative care and not hospice care, he or she will need the services of the nephrology practitioner, the PCP, the family, and home health care providers.
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Section 4: Provider and Practitioner Concerns about Transplant Failure

What Practitioners Say	Causes	Solutions
	<p>What are the problems when patients transition from transplant to dialysis?</p> <p><i>(Note that the causes and possible solutions shown here do not line up. It will be your job to line up causes and solutions for your own clinic.)</i></p>	<p>What can we do to improve collaboration with the transplant team for the benefit of the patient?</p>

What Practitioners Say	Causes	Solutions
<p>“Often incomplete or no information is communicated to me or to the dialysis unit to know what has happened to the patient and what changes need to be made.”</p>	<p>1. The dialysis team often has no information about the patient. They may not know the follow-up plans or whether to expect the transplant to function again. They may not know who will manage the transplant medications, what immunosuppression the patient has used, and whether the patient is a candidate for a</p>	<ul style="list-style-type: none"> • Before accepting the patient, obtain records from the transplant provider and/or the referring nephrologist. • There needs to be nephrologist-to-nephrologist communication about the key information. • Include immunosuppressive plans in your short- and long-term care planning.

	<p>future transplant.</p> <ul style="list-style-type: none"> • The transplant team and the dialysis team have not established a standardized process for sharing of information or plans. Lines of communication are often very informal. • Medical records of the transplant patient may be fragmented between the transplant clinic, an outside nephrologist, and the hospital. 	<ul style="list-style-type: none"> • Identify a “go-to” person in the transplant team, often the head coordinator, who can help with communications and records as needed.
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What Practitioners Say	Causes	Solutions
 <p>“Patients have not been transferred to a local nephrologist after transplant failure until they need dialysis, which means they often start with a catheter.”</p>	<p>2. Patients have not been prepared psychologically or medically for dialysis. This includes the lack of access preservation or planning.</p> <ul style="list-style-type: none"> • The transplant team focuses on preserving a transplant and may lose sight of the need to prepare a patient for dialysis if the transplant function declines. • The transplant may have failed abruptly, so there was no time for access planning. • Patients sometimes refuse to return to their non-transplant nephrologist and instead obtain all their health care from the PCP and/or the transplant team. • Some patients state that they will never agree to dialysis, but change their minds when a transplant fails. • The patient starts dialysis with no HD or PD access other than a tunneled HD catheter. 	<ul style="list-style-type: none"> • Prepare patients who are on the transplant list about the possibility of returning to dialysis at some point. Be sure they know to “save the arm” for a future fistula or to preserve a fistula that is already present. The transplant team needs to “save the arm” from needle sticks and intravenous lines, even if the transplant is functioning well. • Speak with the transplant team(s) about how they collaborate with a nephrology practitioner who is outside of the transplant team. <ul style="list-style-type: none"> ➤ The outside nephrologist may focus more on CKD concerns, including preparation for dialysis (if needed). One option is to alternate visits between the transplant clinic and the non-transplant nephrologist. ➤ Patients with worsening kidney function need repeat education about RRT options and preparation for a dialysis access. If the nephrology team cannot provide that, the patient needs a referral to an

		<p>outside nephrologist.</p> <ul style="list-style-type: none">• Speak with the transplant team about having the patient see the transplant social worker or a counselor if the patient is losing the transplant. They may help the patient through a very tough time.
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CHAPTER 8. TRANSITIONS BETWEEN SETTINGS

Problem: Transitions of care between hospitals, skilled nursing facilities, long-term acute care hospitals, and dialysis clinics present major challenges and safety risks for patients.

Goal: Develop a seamless process for the transition of care between the dialysis clinic and other care settings so that patient care is safe, appropriate, and coordinated.

Part 1: Introduction

Transition of care between settings is a critical part of care coordination and is particularly complex for kidney patients. Approximately 35% of hospitalized dialysis patients are re-hospitalized within one month, often for the same problem that caused the first hospitalization. Good discharge processes can decrease the risk of re-hospitalization, but many other processes are also important for safe transitions. Medical complications, including medication and dialysis treatment errors, occur when providers do not share information. If the dialysis team does not review information from the hospital in a timely manner, critical treatment changes can be missed. We need to consider what to do before, during, and after a hospitalization, as well as how to collaborate with an SNF or LTAC.

Notes: The problems outlined in this chapter are complex. Many of the persons and processes involved are outside the direct control of the dialysis provider.

Dialysis clinics need to lead the efforts to improve care coordination for their patients. Hospitals, SNFs, and LTACs take care of patients with a wide variety of problems. Only a small number of their patients have kidney failure. Many medical personnel do not understand how dialysis clinics work or why the dialysis clinic needs timely and detailed information. Investing time and effort to develop good transition processes should pay off for patient safety and better care and better relationships between patients and providers.

Poor communication is at the heart of many transition problems. Patients rely on their providers to communicate with each other and generally believe that they will do so. Poor communication leads to safety risks and medical errors. They erode the trust that patients have in their providers.

Notes about the role of the EMR in transitions between settings:

In many settings, providers and patients rely largely on EMRs for communications rather than on paper records and fax machines. Unfortunately, many of the EMRs do not communicate with each other, and many providers are unable to view the records in a different provider's EMR. Frequently, the dialysis clinic, the patient, and even the nephrologist cannot view the hospital's EMR and vice versa. Hospital staff may assume that the dialysis staff can use the hospital EMR. These problems result in misunderstandings and affect patient safety. Many hospital EMRs are not designed for dialysis-specific issues, such as viewing dialysis treatment records. Unless your clinic, the nephrologist, and the hospital can all communicate via the EMR, you will need to use paper, a fax machine, and a telephone.

In some locations, many medical providers are a part of Health Information Exchanges (HIEs). As the name suggests, these providers can view medical records from each other's EMRs. The types of medical records they can view include admission and discharge summaries, test results, etc. Currently, most providers in the HIEs are hospitals or large medical practices. The launch of a similar system of electronic information exchange between dialysis facilities is in progress, and a universal, inter-connected system of electronic information exchange between dialysis facilities, hospitals, and other settings is anticipated by the release of the next version of this toolkit.

As with a written report, just because something is in the EMR does not mean that it is accurate (e.g., discharge medications) or appropriate. The EMR may not contain the information needed for dialysis. Review the records in detail and follow up with any questions.

If you can have input into the content of the hospital EMR, tell programmers or HIM personnel what is needed. The nephrologist may be able to help the hospital create an admission and discharge order set designed for kidney patients.

Part 2: Get started

Gather your dialysis team. What problem is most urgent, and what is most critical for patient safety? Decide how to define the problem.

It is necessary to collaborate with staff at the outside setting. This is true even if EMR access is shared. It will be important for them to understand how improving the transition process will benefit the patient and the hospital or other setting (e.g., SNF). The specific staff persons will depend on the addressed problem; that may change as you learn more about the processes in place.

In the dialysis clinic, the transition team may include the charge nurse, the medical director, the administrative assistant, and the social worker. In the hospital, the basic team may be the case manager or social worker, a hospitalist, the inpatient dialysis staff, and the nephrologist. The team may be different for different problems. It may be different at each hospital. For example, you may need to include the Medical Records supervisor to help with record sharing. In an SNF, the transition team may be the nursing administrator or supervisor, an advanced practitioner, and the medical director. Engage the team members by an initial in-person meeting if possible. Get contact information (cell phone, email, office phone) for the team members.

Some, but not most, hospitals already have a team that includes persons such as a discharge planner, a nurse, and/or pharmacist who are "patient-navigators." They help guide patients and families through the transitions from the hospital to an outpatient setting, such as the primary provider's office and/or dialysis. Use this team if it is available.

Start taking steps

The dialysis and hospital (or SNF/LTAC) transition team will need to:

1. Identify what processes, if any, are already in use when patients transition between another setting and the dialysis clinic. It is vital to know details so that you can identify flaws. Be as concrete and specific as possible.
2. Track the problem until understood. Do not rely on anecdotal reports. Real data are necessary to find out what processes to improve.
3. Start asking “why” the process in place did not work. List the causes and the causes of the causes—and keep asking why. Note: There may not be a standardized process in place. Use that as an opportunity to create a process that works.
4. Think of solutions. Solutions must be things over which the dialysis team has control and that will improve the outcome. These include processes for two-way communication and patient/family education. Think about the details that are often overlooked (such as the voice mail being full or that the patient cannot remember the name of the dialysis clinic).

Detailed descriptions of problem solving processes are presented in Chapter 10, “Problem Solving Steps.”

Turn good solutions into **processes** that can be “hardwired” into the working of the clinic. Solutions should not have to be re-invented every time the problem arises.

Dialysis clinics already have many processes in place. The clinic can also create processes to improve patient transitions. For example, have a form that the dialysis nurse faxes to the emergency department and gives to the emergency personnel. It should contain information urgently needed to evaluate the patient including the immediate problem, the problem list, allergies, and medications. Have a process so that a specific person (e.g., an administrative assistant or PCT) checks voice mail messages and faxes and/or EMR records at regular intervals during the day so that the clinic staff does not miss critical messages about patients.

Remember that extra time “up front” will save time and frustration later and will improve patient safety.

Broad Concepts:

1. Embed new processes (“hardwire”) into the routine admission and discharge activities of the hospital, SNF or LTAC, and the dialysis clinic. Work with the hospital or other setting to create the processes. Redesign the processes if they do not work.
2. Remember that communication is a two-way street. The hospital, SNF, and LTAC need information from the clinic. They do not know as much about kidney patients as you do, and they rely on your expertise. They do not know how the dialysis clinic works or what it needs from them unless told.
3. Have a system in place to track and trend transitions. Know if the processes in place are working. Designate a person to maintain a log of transitions and any problems that arise. Transitions between settings are high-risk events. The dialysis team, including the clinic’s medical director, should review them regularly to evaluate improvement possibilities. Anticipate the need to “tweak” the processes in collaboration with the hospital.
4. Caregivers must share information for care coordination. Work with the hospital during a hospitalization so the hospital staff can share information during admission and before discharge.
5. Engage and educate patients and families. Ask for their feedback. However, do not make them the primary source of communication between settings.
6. Do not get into the “blame game.” Cooperation and collaboration are necessary to make transitions safe and efficient.

The following list is a sample of transition problems between hospitals and dialysis clinics with causes and potential solutions. This list is based on surveys of dialysis staff, practitioners, and patients about the problems with transitions between hospitals and dialysis clinics. Also included is a section on SNF (or LTAC) and dialysis clinic transitions. Problems differ by clinic. Hospital systems, nephrology groups, and large medical providers all work differently. There will be different problems, and you will need to devise different solutions (processes) for each situation.

When problems are encountered, **do not start by blaming any one person or group.** Collaborate with providers outside the dialysis clinic. Caregivers want to do the right thing but may not know what is necessary for continuity of care of kidney patients. **Engage patients, but they should not be your main source of information.** Remember that everyone is busy, and creating processes that work for your clinic are essential.

Initial Emergency Department Contact and Hospital Admission

What Providers Say	Causes	Solutions
	<ol style="list-style-type: none"> 1. The emergency department and/or hospital do not have accurate information about the patient and may not even know why the patient was sent there. The patient and/or family do not know why the patient was sent to the hospital. <ul style="list-style-type: none"> • The dialysis clinic does not call the hospital or emergency department 	<ul style="list-style-type: none"> • Establish a "go-to" person or position in the ED(s) to which your clinic sends patients. This is important to assure that key information gets to the practitioner evaluating the patient in the ED. • Always call the ED nurse or

	<p>(ED) and does not send information to the proper place.</p> <ul style="list-style-type: none"> • Communication gaps occur at the emergency department and hospital level. The ED may receive faxed records, but they are not placed in the hospital record. • The patient may arrive in the ED during “shift change” and information is not passed on. 	<p>clinician <u>and</u> send information by fax or other means. If the patient is coming from the dialysis clinic, have a communication form that contains the pertinent patient data. Send this to the ED <u>with EMS</u> and by fax. Confirm arrival of the information.</p> <ul style="list-style-type: none"> ➤ Critical data include a description of the acute event and what interventions were done (e.g., blood cultures, medications). It should also have the problem list, allergies, medications, and contact information for the clinic and the nephrologist. • Do not rely on the emergency medical technicians to relay information, except that which is most pressing. • <u>Do not be surprised</u> when information does not make it from one department to another, including from the ED to the patient floor. • Follow up with the patient’s nurse or doctor to see what information they need from the dialysis clinic. Inform them about when the next dialysis treatment is due and the identity of the patient’s nephrologist (or nephrology group).
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Concerns during a Hospitalization

What Patients/Providers Say	Causes	Solutions
	<p>1. The hospital staff and practitioners do not know enough about the patient. The dialysis clinic may not even know that the patient is in the hospital.</p>	<ul style="list-style-type: none"> • Educate the patient and family about the need to inform the dialysis clinic when a patient is hospitalized. • Give patients the contact information for the clinic and

<p>“We spend hours calling around to hospitals to find patients and even call the police to do a “safety check” when a patient did not come to dialysis, and we can’t reach him/her or any family.”</p>	<p>2. Hospital providers often do not understand the medication, dietary, and other needs of kidney patients. They do not always ask for help from nephrologists.</p> <p><u>Dialysis Clinic Concerns</u></p> <ul style="list-style-type: none"> • The clinic does not know why a patient does not come to the dialysis appointment. The patient and/or family do not or cannot tell the dialysis clinic that the patient is in the hospital. They often assume that the hospital will inform the dialysis clinic. • Hospital staff are busy taking care of the patient. The main reason for emergency staff to contact the dialysis clinic is to get information about the patient, not to inform the clinic of the hospitalization. • No one could reach the dialysis clinic to report that the patient is in the hospital or to get information about the patient. The voice mail may be full or not working, or no one has the clinic’s phone number. 	<p>the practitioner and tell them to keep it with them at all times. Instruct the patient and family to give the contact information to the ED, hospital admissions, and staff. You can give patients several business cards to keep in their wallets.</p> <ul style="list-style-type: none"> • Make certain that the clinic voice mail works so that the patient, family or emergency staff can reach the clinic, even if the clinic is closed. Designate a person to check for messages at least daily.
<p>“The hospital nurses will not share any information with us. We have information about the patient that can help them if they would discuss the patient with us. Sometimes patients could have been discharged sooner, but no one tells us that the patient will need special equipment (like a Hoyer lift) or medications that take a few days for us to arrange, particularly if the discharge is on a weekend.”</p>	<p><u>Hospital Treatment Concerns: Sharing Information</u></p> <ul style="list-style-type: none"> • The hospital, including the acute dialysis staff, does not have outpatient records with laboratory results, treatment orders, medications, etc. • Dialysis and hospital staff will not share information due to concern about patient privacy regulations. • The dialysis clinic does not have access to electronic hospital records. Hospital staff often assume that the clinic 	<ul style="list-style-type: none"> • Ideally, create a patient transition packet. It should contain the patient's history, pertinent exam findings, dialysis prescription, medications, allergies, and diet orders. It can be updated when significant changes occur and reviewed regularly (e.g., at care plan review). It should also have clinic information such as name and location of the clinic, hours of operation, phone, fax, email, etc. The patient and clinic should have

	<p>has access.</p> <ul style="list-style-type: none"> • The inpatient dialysis nurse(s) may not be up to date about the patient’s condition or care planning during the hospitalization. This may be due to lack of communication with the hospital staff or due to lack of continuity within inpatient dialysis staff. 	<p>copies. Instruct the patient to show it to the staff at the hospital and emergency room. You can print much of this packet from the clinic’s EMR (if available) and give it to the patient.</p> <ul style="list-style-type: none"> • Communication is a two way street. Have a process to send records to the hospital as soon as possible, even if the patient already has a copy. If there is a designated inpatient dialysis unit at the hospital, also send records there. • Have a checklist of what information to send. Records should include (at a minimum) the problem list, medication list, allergies, and practitioner contact information. Make sure it is up to date. • Establish a process so that hospital staff can speak with dialysis staff without fear of violating patient privacy regulations. • The hospital may require written consent from the patient to allow hospital staff to speak freely with the dialysis staff. Advise the patient or family to give consent at the hospital. You can tell them that sometimes hospital staff will not share information without written consent. • If the inpatient dialysis staff is routinely not up-to-date, discuss it with the inpatient dialysis supervisor. Discuss the importance of having the hospital dialysis nurses communicate with the hospital providers regarding the patient’s status and care
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<p>Patient: “Transfer to hospital; each time it is slow to get dialysis. After surgery, I have to intervene to make sure dialysis is scheduled. Binders are never given based on my prescription, the food is not appropriate; I am given things I should not eat. Other non-kidney challenges, as well; always issues around my insulin pump. Each hospital has a different policy; they want me to stop my insulin pump therapy and start hospital controlled traditional protocol. There are a myriad of safety issues.”</p>	<p>Hospital Treatment Concerns: <u>Medical Care</u></p> <ul style="list-style-type: none"> • Non-nephrology providers may not understand the complex needs of dialysis patients. They may not recognize the need to get a dialysis treatment done when required. • Non-nephrology providers may assume that the nephrologist knows that the patient is in the hospital. They may think that the dialysis nurses know that the patient is there and will do dialysis when it is needed. As a result, they may not notify or consult the nephrologist. • The patient’s nephrologist does not go to that hospital. • Non-nephrologists often expect that dialysis can be done at a moment’s notice and do not know about the scheduling issues. • Hospital practitioner orders are not specific about medication schedules, particularly those involving phosphate binders, medications that are removed by dialysis, or medication doses that need to be adjusted. The practitioner may assume that the nursing staff or pharmacy will adjust the schedule or dose. • Patients do not speak up about their concerns because they may assume that the hospital doctors and nurses know more than they do about kidney patients. • If patients do speak up (e.g., about medication schedules) 	<p>planning.</p> <ul style="list-style-type: none"> • Notify the patient’s nephrologist or other practitioner that the patient is in the hospital. If the hospital team has not consulted the nephrologist, he or she can request that they do so. The nephrologist is typically the most qualified provider to review a patient’s medications, medication schedule, diet, nutritional supplements, etc. • Nephrologists and renal dietitians can help educate medical, pharmacy, and nursing staffs about the needs of dialysis patients. • Discuss hospital medication and diet problems with the dialysis clinic’s medical director or the inpatient dialysis medical director; he or she may be able to intervene with the hospital’s pharmacy and/or dietary department. • <u>Even before</u> a hospitalization, speak with patients and/or their families about being in the hospital. Encourage them to speak up if diet orders and medication schedules are not right. There may be a good reason for a change, but the patient needs to know.
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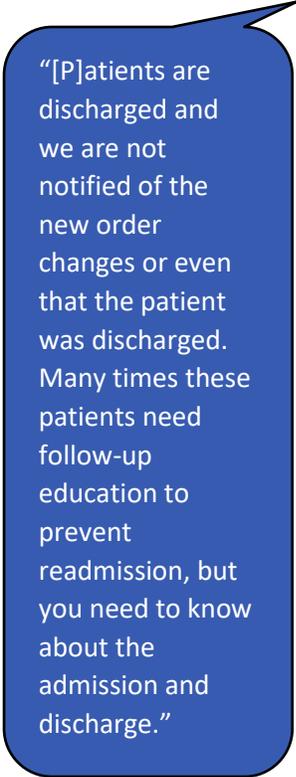
	<p>changes are not made because the staff is busy or does not understand why a change is needed.</p>	
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Hospital Discharge Planning

What Patients/Providers Say	Causes	Solutions
<div data-bbox="240 541 506 877" style="border: 1px solid black; border-radius: 15px; background-color: #4a7ebb; color: white; padding: 10px; width: fit-content;"> <p>“Other clinics seem to think the dialysis clinic handles all aspects of care for the patient.”</p> </div>	<p>1. Hospital discharge planning is often incomplete, and patients are discharged prematurely and/or before outpatient follow up arrangements completed.</p> <ul style="list-style-type: none"> • Non-dialysis providers and patients often do not know what the dialysis clinic can and cannot provide, such as transportation, cardiac monitoring, and dressing changes of infected wounds. • If the patient has home health care services following discharge, the home care agency communicates with the PCP and not with the dialysis provider. 	<ul style="list-style-type: none"> • Establish a communication process between the dialysis clinic and the hospital discharge team (usually case management or social services). • Talk frequently with the discharge team and the inpatient dialysis nurses. The dialysis nurses can share information about the patient’s dialysis treatments. Important information may include if the patient can transfer with minimal assistance or can sit in a chair for hours. • Create an information sheet for the case managers, other hospital team members, and the PCP. The purpose is to tell them what dialysis clinics can and cannot provide. This should be part of a standardized information packet shared with hospital case management. It can be re-sent to the hospital when a patient is admitted. <ul style="list-style-type: none"> ➤ For example, often a patient requires intravenous medications that are not on the dialysis clinic’s formulary or that need specialized monitoring. The medication may have to be given elsewhere. • If appropriate, speak with the patient and/or family about safety concerns, such as the need for physical rehabilitation

		<p>or other services, particularly if the patient is reluctant to use them. They may listen to a familiar person better than they listen to hospital staff.</p> <ul style="list-style-type: none"> • Find out if the patient has home health care, including visiting nurse services, physical therapy and/or occupational therapy, following the hospitalization. If so, ask for the name of the home provider and communicate with him or her regularly. This may prevent another hospital visit. • The solutions listed here should also be considered for patients in an SNF or LTAC.
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Hospital Discharge Information and Orders

What Practitioners/Staff Say	Causes	Solutions
 <p>“[P]atients are discharged and we are not notified of the new order changes or even that the patient was discharged. Many times these patients need follow-up education to prevent readmission, but you need to know about the admission and discharge.”</p>	<p>1. The dialysis clinic does not receive a hospital summary, discharge plan, or treatment orders when the patient is discharged from the hospital.</p> <p>Hospital Information</p> <ul style="list-style-type: none"> • No discharge summary is available. • The practitioner who discharges the patient assumes that records will automatically get to the dialysis clinic. • The nephrologist and/or the hospital dialysis nurses did not know about the discharge plans. • There is no process in place to send hospital records to the outpatient dialysis clinic. Records are sent to the doctors who saw the patient in the hospital, plus the PCP, but not to the dialysis clinic. • The patient’s dialysis clinic may not be identified in the medical record. EMRs do not have a 	<ul style="list-style-type: none"> • Define what information is needed (e.g., change in medications, new diagnoses, new allergies) and when it is needed (before the next dialysis treatment). <u>Use a checklist.</u> (See the appendix for sample checklists that your clinic can modify.) • Work with the case manager or discharge planner at the hospital. He or she can help ensure that information is sent to the dialysis clinic. • If possible, obtain access to the EMR systems of the hospitals where your patients go most often. EMR access should at least be available for the nurses and practitioners. • Identify the department that manages discharge information at the key hospitals. This could be case

	<p>specific field for that information. The medical records department does not know where to send the discharge information.</p> <ul style="list-style-type: none"> • The dialysis clinic cannot find the discharge information in the stack of faxes! Yes, this happens. 	<p>management, medical records, or the HIM department. Meet personally with the lead person of that department. Explain the problems of the dialysis transition and work through any HIPAA problems. Arrange a process so that discharge summaries are routinely sent to the dialysis clinic just as they are to the PCP.</p> <ul style="list-style-type: none"> • Communicate with the inpatient dialysis unit about discharged patients. The dialysis nurses should be able to relay the most recent laboratory results and what procedures were done. They may be able to send records if necessary.
	<p><u>Discharge Dialysis Orders</u></p> <ul style="list-style-type: none"> • The nephrologist may not know that the patient was discharged. • The hospital nephrologist does not send orders despite knowing about the discharge. • There is no standardized process for sending orders or other reports to the dialysis clinic. It is not included in any discharge checklists or EMR processes. • The nephrologist may not have immediate access to vital information, including a change in the post-dialysis target weight, EPO dose, antibiotic needs, etc. The information may be in a locked room, or the nephrologist may be at another location. • Information needed for new treatment orders (e.g., post-dialysis weights or time) may be difficult to find. Dialysis treatment records may not be in 	<ul style="list-style-type: none"> • Work with the hospital staff (discharge planner, patient’s nurse, etc.) to make sure that dialysis orders are written before the patient can be discharged. • Have a checklist of orders that the dialysis clinic needs in order to treat a patient. (See appendix for sample checklists.) • Ideally, do not start a treatment without new orders following a hospitalization. • <u>Standardize</u> a process for use when no orders are received. • Contact the patient’s practitioner to review orders based on the available information. • If the practitioner has no information about the hospitalization, <u>standardize</u>

	<p>the EMR.</p> <ul style="list-style-type: none"> • The nephrologist cannot reach the dialysis clinic because the voice mail is not working or is full, or no one checks it. • The nephrologist does not know where to send post-discharge orders. • Someone sent orders, but they are buried in a stack of faxes. 	<p>a process to obtain the discharge information <u>before</u> starting the dialysis treatment. The clinic needs data about events (e.g., infection) and treatments, changes in care plans and medications. The inpatient dialysis team should be able to help. Review the plan and orders with the dialysis practitioner and obtain approval. If the practitioner or associate is frequently unavailable or unwilling to review or provide updated orders, discuss with the medical director and/or clinic administrator.</p> <ul style="list-style-type: none"> • “Flag” the records of patients who were recently discharged so that the practitioner knows to review medication and treatment orders. <u>Timely, focused visits following hospital discharge (preferably within two treatments) are associated with fewer re-hospitalizations.</u> • <u>Track</u> which hospitals and which nephrologists (or nephrology groups) do not send discharge information and orders. Engage the nephrologist and other key persons, including the acute hospital dialysis team, to discuss solutions.
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Medication Errors

What Practitioners Say	Causes	Solutions
	<p>1. Medication errors occur when the patient is discharged from the hospital. <u>Dialysis to Hospital Medication Issues</u></p>	<ul style="list-style-type: none"> • The dialysis clinic should have a process to verify and update medication lists regularly. • Educate patients to keep

	<ul style="list-style-type: none"> • Hospital providers do not have accurate admission medication lists. The medications that the patient is taking may be different from the lists at the dialysis clinic, the PCP office, and even the pharmacy. • The dialysis clinic medication list may be incorrect. It may include both generic and brand name forms of a medication with different doses. 	<p>updated copies of their medication lists and allergies with them at all times.</p> <ul style="list-style-type: none"> • Give patients tools (lists, forms) to maintain medication lists. (See the appendix for samples.) <p>The best way for the clinic to maintain the list is to have the patient bring in the actual medication bottles and boxes rather than just review the list. You can also call the pharmacy.</p>
<div data-bbox="180 695 483 1402" style="background-color: #4a7ebb; color: white; padding: 10px; border-radius: 15px; width: fit-content;"> <p>“Hospital discharges are... difficult transitions because the patients are confused about medication changes and often take more than one medication from the same class because they are switched in the hospital and the medication is not stopped on discharge.”</p> </div>	<p>Hospital to Dialysis Medication Issues</p> <ul style="list-style-type: none"> • The hospital may substitute different medications because the hospital formulary is limited. The practitioner who writes the discharge orders may continue the medication given in the hospital rather than the medication the patient was taking before the hospitalization. This is common for cholesterol lowering medications, blood pressure medications, and for medications used to block stomach acid. • Anemia medications may be given by a different route or by a different schedule in the hospital. The prescription needs to be changed for the outpatient clinic. • The dialysis unit does not know if medication reconciliation at the time of the hospital discharge is accurate. A pharmacist may not have reviewed it. • The discharging doctor may not reconcile the admission medication list with those given in the hospital and those that should be ordered at discharge. For example, phosphate binders may have been held during the hospitalization due to surgery, and no one thought to re-order them at discharge. • The format of medication instructions is often poorly organized and confusing. 	<ul style="list-style-type: none"> • Have the patient bring in <u>all</u> of his or her medication bottles and boxes <u>and</u> the discharge medication instructions. This should include medications that were stopped or changed. • The dialysis RN should review the medication bottles and list for errors, duplications, omissions, etc. If the ordered medications are different from what the patient is actually taking, confer with the practitioner to correct them. • Have the dialysis practitioner review the medications as soon as possible after a discharge. <u>Flag</u> the charts of recently discharged patients. • Fax the medication list to the practitioner. • Make sure that the patient understands medication instructions. • Ideally, the medication list should include the name of the prescribing clinician and the reason for taking the medication. • If the prescribing clinician was not the patient’s nephrologist or PCP, find out who will be responsible for ongoing refills

<p>“Hospital discharges— understanding indications for and doses of new medications, making sure antibiotics are continued, changes in diabetes and BP management in a hospital setting, new adverse drug reactions and interactions— computerization does NOT ensure safe medication reconciliation.”</p>	<ul style="list-style-type: none"> ➤ Both the generic and the brand names of medications may be listed. If the format is confusing, the patient may not know that they are the same medication. ➤ If only those medications that were changed are re-ordered, it may not be clear to patients what medications they need to stop, start, or change. • The discharging clinician may not know why a particular medication is needed and may omit it from the discharge medication list. • New medications may be too expensive and/or not on the patient’s health insurance formulary. • New medications that are not appropriate for kidney patients may be ordered without the knowledge of the nephrologist. An example would be one of the blood thinners that should not be given to dialysis patients. The pharmacy may not be aware that the patient is on dialysis, so does not question the prescription. • If a patient is confused, or if the instructions are not clear enough, he or she may simply resume the old medications. • Medications that are normally given to a dialysis patient may not be on the discharge medication list, so that medications for anemia or mineral metabolism may not be included. 	<p>and monitoring of that medication. Otherwise, the patient may be unable to obtain refills since no one has that responsibility. This is often a problem for medications prescribed for pain, sleep, and/or depression.</p> <ul style="list-style-type: none"> • If necessary, contact the inpatient dialysis staff about medications given on dialysis.
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Conflicting Messages

What Patients Say	Causes	Solutions
	<p>1. Messages given by the hospital staff may be different from those of the dialysis staff. This can cause confusion and distrust on the part</p>	<ul style="list-style-type: none"> • Dialysis staff are often in the position of clarifying what another provider has told the patient. Determine if the

<p>“Hospital staff that does not know you that try to tell you something different than what your regular nephrologist tells you.”</p>	<p>of the patient.</p> <ul style="list-style-type: none"> • Medical conditions may have changed, and that was not made clear to the patient. The patient did not understand that things could change. • Not all medical personnel, including nephrology practitioners, will agree on a single course of action. Practitioners may not make it clear that there is not always a single right answer and that there are legitimate differences of opinion. • Some patients and families are frustrated with the fact that there may be differences of opinion. This can be very disorienting to patients with complex medical conditions. • Providers who are not familiar with the needs of dialysis patients may give bad advice (e.g., drink more water). 	<p>outside advice was right for the patient. Some advice will clearly be wrong (e.g., medication doses or “drink more water”), but sometimes it will be difficult to know. Discuss questions with the practitioner.</p> <ul style="list-style-type: none"> • Explain that there can be legitimate differences of opinion. Clarify any discrepancy and discuss the changes with the patient. Involve the dietitian, the social worker, the nephrology practitioner, or the patient’s PCP.
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Dialysis to/from SNF or LTAC Transitions

What Practitioners/Providers Say	Causes	Solutions
<p>“One difficulty is the transition from hospital to long term care while also keeping the dialysis unit informed.”</p>	<p>1. Communications between the SNF or LTAC and the dialysis clinic are often poor. The practitioners at the SNF/LTAC may be unfamiliar with the unique needs of kidney patients.</p> <ul style="list-style-type: none"> • The hospital sends discharge records and orders to the SNF/LTAC, but not to the dialysis clinic. • The practitioners at the SNF/LTAC are not nephrologists and may be unfamiliar with dietary and medication needs of kidney patients. • In some areas, LTAC patients go to the outpatient dialysis clinic for 	<ul style="list-style-type: none"> • Develop a collaborative relationship with the SNF/LTAC. You can help each other. Sharing information is essential for continuity of care and does not violate privacy regulations. • Identify a “go-to” person or position at the SNF/LTAC with whom the clinic can communicate when needed. • The SNF/LTAC should send information at each treatment appointment just as they do when the patient goes to a doctor appointment. It should include the most recent medication administration record, the vital signs before

“The problems with communication and with appropriateness of overall medical care are compounded when the patient is not discharged home, but rather to a nursing home where the nursing home assumes they are sufficiently knowledgeable about ESRD care to assume management of all of the medications, etc.”

treatments. In this case, the nephrology practitioner has limited opportunity to review the patient records.

- SNFs/LTACs may not send relevant records with the patient to his or her routine dialysis treatments.
- If patients with poor self-care skills get their meals in a dining room, they may not follow their diet orders or fluid restrictions.
- Patients often receive phosphate binders on a set schedule and not with meals.
- The dialysis clinic does not receive copies of the medication records.
- The nephrology practitioner generally does not have privileges at the SNF and possibly not at the LTAC. Changes in treatments or medications may be delayed if the SNF/LTAC practitioner must approve or cosign orders made by the nephrologist.
- Transportation can be a challenge. A SNF/LTAC may not know that dialysis clinics run on tight schedules and patients must be on time. At the end of a treatment, patients should not have to sit in the waiting room for long periods waiting for transportation.

transfer, and whether there has been a change in status or any acute event.

- Send communications back to the SNF/LTAC with the patient. This can be as simple as that the patient had a stable dialysis. It may be a more complex report if there were difficulties. It should also include new orders or recommendations. (See the appendix for a sample communication form.)
- Update each other about changes in functional status. This may be essential to prevent a hospitalization.
- Some clinics maintain a communication book for each patient. The book goes with the patient to the SNF and to treatments.
- If the patient needs changes in medications, medication schedules, or diet, call the nurse or dietitian at the SNF/LTAC. Also, send a written order with details of the change.
- Communicate with the SNF/LTAC about the needs of dialysis patients. Prepare educational information that includes the need for patients to be on time for treatments. Provide specific information about medications, phosphate binders, dietary needs, and whether to hold certain medications before treatments. Include contact information for the dialysis clinic.
- Review the SNF/LTAC full

		<p>medication administration record at least monthly.</p> <ul style="list-style-type: none"> • Make laboratory results available to the SNF. Send or fax laboratory flow sheets or individual reports. • Request that the SNF/LTAC share documentation of care planning with the dialysis clinic. Share dialysis care planning with them. This should include observations about the patient’s functional status.
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Discharge of a Patient from an SNF to Home

	Causes	Solutions
	<p>1. Discharge from an SNF to home is associated with a high rate of hospital admission and ED usage, similar to the problems seen following hospital discharges.</p> <p><i>Note: This is an issue that does not directly involve the dialysis clinic, but the dialysis clinic may be able to influence the problem.</i></p> <ul style="list-style-type: none"> • Medication reconciliation and other discharge instructions may be unclear and/or are not sent to the dialysis clinic. • The home health care agency may communicate with the PCP, but not with the dialysis clinic. The dialysis unit has valuable information about the patient’s functional status. 	<ul style="list-style-type: none"> • The SNF should send the dialysis clinic the same medication list and discharge instructions that it sends to the PCP. Work with the contact person at the SNF to plan for this. • The use of home health care services is associated with fewer hospitalizations and emergency department visits. • If the SNF does not arrange home health services, the dialysis practitioner or PCP can do so (if needed). • Communicate and collaborate with the home health service to improve the patient’s functional status and avoid another hospitalization.

CHAPTER 9. HEALTHCARE TRANSITION FROM PEDIATRIC- TO ADULT-FOCUSED DIALYSIS SERVICES

Problem: The healthcare transition from pediatric- to adult-focused services can be challenging for patients, their families, and healthcare providers.

Goals: Help healthcare providers identify the challenges of care transitions for adolescents and young adults, create plans for care transition preparation, and increase collaboration between pediatric- and adult-focused dialysis clinics.

In 2012, the USRDS reported that 1,161 children ages 0–19 years began renal replacement therapy (RRT). Of these, 44% were transplanted within the first year of ESRD onset. As of the end of 2012, the number of children with ESRD was 7,522 (73% had transplanted, 15% were on HD, and 12% were on PD).

The main causes of ESRD in children are congenital/hereditary disorders (50%) and glomerular disease (25%). Unlike adults, less than 2% have diabetes as a cause of ESRD.

Part 1: Introduction

What is different about the pediatric model of care compared to the adult model of care?

In the **pediatric model of care**, parents (or guardians) are in charge of the care. They make decisions, monitor the child's health and treatments, give consent, make appointments, provide transportation, and are responsible for finances and payment. Ideally, they are with the patient at each step of the way.

In the **adult model**, patients manage their own care. They make decisions, give consent, schedule appointments and transportation, and are responsible for finances and payment. A parent is not present at each healthcare encounter. Providers need consent from the young adult to involve the parents, even though he or she may still be highly dependent on them.

What is unique about adolescents and young adults with kidney failure?

1. Chronic kidney disease consequences include:

- These patients miss out on school and socialization due to illness, hospitalizations, and procedures.
- Some have anomalies that affect growth (short stature), development, and/or other physical effects.
- Some adolescents have (or grew up having) enuresis, which has both psychological and social effects.
- Cognitive, educational, and psychosocial development are often delayed or impaired. As a rule, the longer the patient has the disease, the more severe the impairment is. This may prevent them from achieving self-management or independence. They may rely on parents all their lives.

- Patients with kidney failure are also impaired by feeling ill, the need for dialysis, and multiple medications.
- They may demonstrate an increased reliance on family.
- They may experience fears about their own morbidity and mortality.
- Anxiety and depression are common.
- Patients with long-term kidney disease often have the same comorbidities as older patients, such as cardiovascular disease and sudden death.

2. Psychosocial characteristics of adolescence include:

- Experimentation, inconsistent behavior, feeling invincible, and lack of future orientation
- More concerned about body image and peer acceptance than the consequences of chronic disease
- Increased risk of non-adherence and transplant failure
- More importance placed on being like one's normal peers than taking control of one's medical needs
- May not be mature enough to understand medications and diseases, even though they may be able to repeat the names

3. What about their families or teachers?

The relationships between young patients with kidney failure and the adults in their lives are characterized by:

- Family, teachers, and even health professionals are often very protective. This may delay maturation and development of self-advocacy.
- Healthy siblings compete for "parent-time."
- Family cohesiveness and support may fail in the face of serious chronic illness in a child.
- A well-adjusted and supportive family is associated with better coping skills by the patient and better preparation for adult responsibilities.

How is a pediatric clinic different from an adult clinic?

- Pediatric clinics have higher staff to patient ratios and more family involvement. Staff members understand adolescent developmental stages. They know how to cope with immature behavior. They have more access to interdisciplinary services (e.g., recreational therapy).
- Pediatric providers see patients more frequently.
- Adult-focused providers expect patients to be autonomous. The level of support is generally less than in a pediatric clinic.
- Adult-focused providers may marginalize family if they do not understand the dynamics of the transition.

What are the challenges for adolescents and providers in the adult-focused dialysis units?

- For the young patient, the new world of adult care is complex and overwhelming. For example, many pediatric clinics are in a university setting where all the medical services are on the same campus. In the adult world, medical services are separated. Different providers may not communicate well with each other. The patient must go to a new pharmacy, a subspecialist across town, a PCP in another location, etc.
- The adolescent must be able to articulate what his or her kidney disease is, know medications and allergies, and report his or her own medical history. **These are often challenges even for mature adults.**
- Patients often have comorbidities due to congenital or hereditary disorders.
- Many pediatric disorders are unfamiliar to nephrologists who largely treat adult patients.
- Of course, not all patients have to change clinics when they reach a certain age. Many clinics that serve a largely adult population have a small number of pediatric patients. These young patients must also transition to an adult model of care.

Why is a transition plan necessary?

The number one cause of kidney transplant loss in adolescent patients is non-adherence to medications and treatment plans. Patients between the ages of 14 to 16 years have the greatest risk of transplant failure. We do not know if dialysis patients have more complications when they transfer from a pediatric to an adult clinic. However, **providers and patients often report that the transition is challenging and potentially unsafe.** Some pediatric dialysis programs have found that a structured transition program decreases the number of emergency department visits and hospitalizations for young kidney patients.

The **responsibility of preparing the patient and family for the transition** from the pediatric to the adult care model **will fall largely to the pediatric clinic, but needs to continue in the adult care settings.** The pediatric clinic will need to educate the adult providers about what has been done to evaluate and prepare the young patient for transfer of care. The adult clinic must continue the transition process. They must tailor it to the patient's development, culture, and literacy level. Patients who grow up in a "mixed" clinic (has both adult and pediatric patients) also benefit from a structured transition plan.

A transition coordinator is a valuable resource for any clinic that must manage pediatric to adult transitions. This person does not need to be a nurse or social worker, but needs to have adequate training (just as in the case of patient navigators). Adult clinics that have few or no young patients may need to adjust staff and practitioner time to meet the needs of these patients. Transition readiness, preparation, and self-management education can occur during regular dialysis visits.

Patients and families may resist the transfer from a pediatric to an adult clinic, or, alternatively, patients may initiate a transfer prematurely. When patients transition, family members must also do so. Because parents are present at many or all dialysis treatments, they often develop bonds and informal support groups that they leave when the patient transfers to a different clinic. Pediatric staff members feel protective of patients for whom they have cared during extremely vulnerable times. Sometimes they

cared for patients for as long as 20 years. They may have concerns about what will happen after the patient's transition.

Common Features of Structured Transition Programs:

- Transition preparation begins at age 12-14 years. It is a part of ongoing care planning.
- Patients are prepared with positive messages about the transition to adult care.
- Transition readiness is assessed with structured surveys that need to continue to be used in the adult setting.
- Patients are taught “competencies” needed for self-management. To do so, programs use standard templates for preparation and transfer. They re-assess the patient's progress at regular intervals (yearly).
- Transitioning is done gradually. It is appropriate to the patient's developmental stage and intellectual ability.
- Parents are included in the plan and asked for input. Their presence at clinic visits is gradually lessened so that the patient gains more self-management skills and independence.
- Programs use a medical “passport” as a patient/provider communication tool and patient education tool.
- Programs use a standardized tool for medical information transfer to the adult provider.
- Programs understand that patients are not yet fully prepared for adult responsibilities just because it is time for them to transfer care.
- They orient the patients to the adult care providers (assuming the patient must transfer to a new clinic), including meeting with adult providers prior to the actual transition.

Resources

Several excellent free resources are available online that outline steps to assess the readiness for transitions and to guide patients, providers, and families in making the transition from adolescent to adult care. Some of the programs are directed at young persons with chronic disease of any sort, and some are either kidney-specific or have sections for kidney disease patients. The appendix to this toolkit includes a list of resources with links to many of the transitions programs, as well as templates that can be used for letters, “medical passports,” and other tools.

Part 2: Get started

Gather the team. Decide how to define the problem. Start asking why the transition may be difficult. List the causes and the causes of the causes—and keep asking why. Then consider solutions. Solutions must be things over which you have control that will improve the outcome.

If patients must transfer from a pediatric to an adult clinic, the team ideally should include personnel representing both adult and pediatric dialysis clinics.

It is best if “transition champion(s)” can be identified, whether patients must transition between clinics or if the transition to the adult model of care occurs within a mixed adult and pediatric clinic. A transition champion is the person who can help move the process along and is the “go-to” person for transition-related issues. The person can be any member of the health team, including non-medical personnel (e.g., trained college students). He or she may be a nurse who has taken care of the patient most frequently.

Turn good solutions into processes that can be “hardwired” into the working of the clinic. Solutions should not have to be re-invented every time the problem arises.

Dialysis clinics already have many processes in place, such as assigning a specific person to check water quality at designated intervals. The clinic can create other processes for improving the patient transition experience. Examples include designating a “transition champion” for any patient who graduated from a pediatric to an adult model of care and a pediatric clinic creating a transition “packet” to be sent to the adult clinic that includes information about the patient’s progress in achieving the milestones of “competencies.”

What can the dialysis clinics do to improve pediatric to adult treatment transitions?

Some problems and potential solutions apply to clinics that serve only pediatric or only adult patients. Some apply equally well to clinics that serve all ages. Issues of development, maturation, self-advocacy, independence, consent, and guardianship are common to any clinic that serves adolescents or young adults. All clinics will benefit by incorporating structured transition tools in their care. This also includes an evaluation of whether the patient is prepared for the transition and what “competencies” he or she has achieved. The table lists common problems encountered during pediatric to adult care transitions and suggested actions to mitigate these problems.

Problems	Solutions
<p>1. Transition planning</p> <ul style="list-style-type: none"> Lack of planning for the transition may occur. Patient preparation for adult responsibilities may be incomplete. 	<ul style="list-style-type: none"> Make a transition plan. Professional organizations recommend that planning should begin around 12-14 years of age. <ul style="list-style-type: none"> ➤ Begin discussions with the patient and family long before the actual transition. Present the transition to an adult clinic as a positive achievement (e.g., the patient “graduates”). ➤ Gradually assist the patient with self-management skills. Start with suggestions that he or she may later wish to see the practitioner without the parents. Gradually increase the time spent “solo” with the patient. Discuss plans for schooling and employment. ➤ <u>Assess</u> the patient and family’s readiness for self-

	<p>management.</p> <ul style="list-style-type: none"> ➤ <u>Track</u> the patient’s progress over time. Use assessment and tracking tools such as those in “Got Transition,” “STARx,” or “Good-2-Go.” (See appendix for these resources.) ➤ Self-management competencies include, but are not limited to, knowledge of the disease, medications and what they are for, dietary needs and restrictions, ability to make appointments and arrange to get to them, and who to call in an emergency. ➤ <u>Competencies may be transient in adolescence</u>, so they should be reassessed regularly. ➤ Foster independence. Keep the young patient involved in discussions of the disease, treatments, etc. Discuss matters of sexuality, including contraceptive advice. ➤ Assist with transitions to other adult practitioners (e.g., an internist, a gynecologist). A urologist familiar with congenital uro-genital anomalies is often critical. • For the patient who must transfer from a pediatric to an adult clinic, <u>individualize</u> the timing of the transition to the patient. Focus on self-management skills. Base the timing on patient readiness rather than on age. <ul style="list-style-type: none"> ➤ If a transition is mandatory (e.g., due to age), discuss any areas in which self-management skills are poor with the adult clinic. ➤ If possible, delay transition from a pediatric to an adult clinic until the patient is able to verbalize the competencies. ➤ Avoid transfer at a time of crisis (e.g., medical instability, start of college or family issues). Avoid transfer before the first year of college or school education is complete. • The patient should have access to support from pediatric providers for a period of time following the transition. Find out what is available.
<p>2. Transfer to an adult clinic</p> <ul style="list-style-type: none"> • Pediatric centers for kidney failure patients are generally separate from, and may be geographically distant from, their adult counterparts. 	<ul style="list-style-type: none"> • If possible, have the patient and family visit the adult clinic and meet with key personnel prior to the transfer of care. Ideally, this should include the practitioner, the social worker, and primary nurse. If feasible, they may visit several different clinics to choose the one they like. It is useful for the social

	<p>worker or transition coordinator from the pediatric clinic to go with the patient and family.</p> <ul style="list-style-type: none"> • Ideally, joint rounds with the pediatric and adult practitioner or dialysis team members should be done. If visits in person are not feasible, consider other options, such as “Skyping” or telemedicine. • To the extent possible, the pediatric clinic can identify adult clinics that have an interest/experience with adolescents and young adults to assist with gaining expertise.
<p>3. Communication between providers</p> <ul style="list-style-type: none"> • Adult clinics may not receive complete patient history or short- and long-term care plans. 	<ul style="list-style-type: none"> • The pediatric clinic should prepare and maintain a multidisciplinary medical summary that is portable and accessible. • Provide relevant information to the patient and assist the patient in developing his or her own “medical passport.” Passports contain information about medical history, medications, practitioners, etc. (See appendix for sample passports.) • The pediatric clinic needs to communicate patient competencies and deficiencies to the adult unit prior to the transition. • Inform the accepting dialysis team of treatment plans, particularly for patients who have treatable or containable conditions such as lupus, cystinosis, or oxalosis. Convey the extent of previous immunosuppressive therapy. • Communication between providers and practitioners is critical. Use a dedicated transition coordinator or champion to spearhead patient transitions and facilitate communication between clinics and providers/teams.
<p>4. Expectations of the adult clinic</p> <ul style="list-style-type: none"> • Adult clinics expect the individual to be autonomous and capable of self-management. They may not be equipped to manage complex developmental issues or cope with immaturity and erratic behavior. • The dialysis team in the accepting adult clinic may not know where an adolescent or young adult is in the 	<ul style="list-style-type: none"> • Adult and “mixed” clinics can designate a pediatric “champion” whose responsibility is to ensure communications, put the patient in contact with a peer group, help the rest of the team identify problems, monitor medication adherence, etc. A “champion” may be a nurse or a social worker. • The adult provider staff should meet with the family ASAP, even if the patient has been attending treatments at the pediatric clinic on his or her own. Discuss their anxieties about the transition.

<p>continuum of development from childhood to adulthood.</p> <ul style="list-style-type: none"> • The short contact time with practitioners in the adult clinic limits the practitioner’s understanding of the patient. • Adult clinic staff may consider parental involvement as intrusive at a time when the young patients are still in need of significant parental support. As a result, adult clinic visitation policies, for example, may be “user-unfriendly” for adolescents and young adults. 	<ul style="list-style-type: none"> • Key persons, including practitioners, need to allot extra time for interaction with and evaluation of the patient. • The adult clinic should use assessment and tracking tools like those in “Got Transition,” “STARx,” or “Good-2-Go,” even if the pediatric clinic did not use them. • Review developmental issues in patient care conferences. <ul style="list-style-type: none"> ➤ Review the references for milestones of developmental stages. Use checklists to assess and document the patient’s progress. (See appendix for milestone references and checklists.) ➤ Involve the family while working on gradually increasing patient autonomy and self-management. Set goals with input from the patient and family. ➤ Incorporate educational and vocational planning into the transition plan. • The adult clinic should be flexible with parents being present during dialysis, especially during the initial transition. Gradually reduce the amount of time the parent spends in the clinic during treatments. Individualize it to the needs of the patient. Young patients still need parental involvement, including at dialysis visits. The transition process is not complete just because the patient reaches a certain age or has transferred to a new clinic. • The adult clinic should contact the pediatric clinic with concerns and questions. • The adult clinic should inquire about what pediatric services are still available to the patient once he or she has transferred.
<p>5. Adult clinic preparations</p> <ul style="list-style-type: none"> • Clinics that serve only adults or that have a small number of young patients are often unprepared to meet the psychosocial needs of adolescent or young adult patients. 	<ul style="list-style-type: none"> • Confidentiality is a high priority for the young patients. When possible, talk to the patient alone, without the parents, to foster independence and self-management. Obtain consent to discuss issues with parents. Fostering respect of the patient and empowerment will improve the transition. • Understand the importance of family, school, and peer group support to adolescents and young adults. • Define acceptable behavior, including the responsibility to be on time and follow clinic rules (e.g., regarding eating on dialysis, visitors); some rules may be different

	<p>from those of the pediatric clinic.</p> <ul style="list-style-type: none"> • Make sure the patient and family know that there may be differences in advice and/or medications compared to the pediatric clinic. • Focus on maintaining staff continuity for young patients. • Promote school and/or vocational training. <ul style="list-style-type: none"> ➤ Suggest nocturnal shifts or home treatment so that the patient can go to classes. ➤ Provide Wi-Fi access for online classes. Encourage patients to bring laptops and do their homework. ➤ As much as possible, adjust schedules so that the patient can attend classes. Let patients and families know that it may not be possible to satisfy all requests. • Discuss issues of recreational drug use, sexuality, contraception, piercing, tattoos, and other topics. • Patient care plan meetings should include issues of maturation, independence, self-management, self-esteem, peer relations, etc. Include the patient. • The adult clinic should engage outside resources, including counseling services if necessary and available. Pediatric specialty clinics and hospitals may have resources that the patient can use even after the transition to the adult clinic.
<p>6. Adult clinic adjustments</p> <ul style="list-style-type: none"> • Adult and “mixed” clinics generally have few or no other young patients who can provide peer support. They tend to be large and have many very ill and elderly patients. This may be very disturbing for young patients. • Many parents request more isolation for young patients. • Adult clinic staff-to-patient ratios are generally lower than in pediatric clinics. Practitioners and clinic staff have less time to spend with each patient in adult clinics. 	<ul style="list-style-type: none"> • If possible, introduce the patient to other young patients at the clinic. Schedule young patients so that they can socialize at the clinic. Matching a patient with a successful young adult mentor may be very helpful. • Make patients feel special. <ul style="list-style-type: none"> ➤ Make a “youth-friendly” section of the clinic. This may be as simple as having a corner with brightly painted walls. • Encourage patients to attend camps for young adults with chronic illnesses and participate in activities with other young patients at the same clinic. • Adjust staff ratios and practitioner time to have more time with the patient. Focus on psychosocial and adherence issues. While more expensive, it will pay off in terms of hospitalization avoidance, improved adherence, and patient/dialysis team satisfaction.
<p>7. Consent and guardianship</p>	<ul style="list-style-type: none"> • Understand consent requirements in your state. Once a

<ul style="list-style-type: none"> • Consent issues and guardianship (when necessary) often have not been clarified for patients who reach the age of consent. The age at which a minor can give consent varies by state. 	<p>patient reaches the age of consent, he or she must give consent for providers to involve parents in decision-making and communications.</p> <ul style="list-style-type: none"> • Obtain consent to communicate with parents or guardians at the patient’s age of consent. • If a patient is not expected to become independent, make sure legal guardianship is established <u>before</u> the patient reaches the age of consent. If the patient must transfer between clinics, the pediatric clinic should work on guardianship.
<p>8. Adult clinic experience in medical conditions of young patients</p> <ul style="list-style-type: none"> • The adult nephrologist may not have expertise in conditions like cystinosis or oxalosis. Pediatric patients often have a long list of problems and surgeries that are different from those of older patients. • Practitioners may not realize that young patients with long duration of disease often have comorbidities generally associated with older age, particularly cardiovascular disease. They are at high risk for vascular access problems and myocardial infarction due to disease duration and/or chronic steroid use. 	<ul style="list-style-type: none"> • For adolescents with uncommon congenital and hereditary diseases, the pediatric team can provide the adult team with concise references regarding the disease, its course, and its treatment. References should be appropriate for the target audience—meaning nursing resources for nurses, physician resources for practitioners, etc. • Keep disease-specific references and websites available to clinic staff. • Maintain usual adult screening evaluations (e.g., lipids) and management, especially those for cardiovascular disease. • Make sure the dialysis team is aware that the patient, despite young age, is at risk for complications usually seen in older patients.
<p>9. Patients post transplant</p> <ul style="list-style-type: none"> • Dialysis units must be prepared to accept the young patient who is transitioning from a failed transplant to dialysis care. 	<ul style="list-style-type: none"> • Just as with any other modality change, patients and parents should be educated about the possibility of transplant failure. • Communicate with the transplant provider and practitioner. (See the Modality Change chapter.) The clinic needs psychosocial as well as medical history information, long-term plans, immunosuppressive history, etc. • Address psychological issues resulting from loss of transplant. Make referrals to outside counseling if necessary. Acknowledge and discuss the loss.

CHAPTER 10. PROBLEM SOLVING PROCESSES

There are many ways to approach problem solving. The first process described here differs slightly from the usual PDSA (Plan-Do-Study-Act) format of defining the problem, gathering a team, defining barriers and root causes, devising solutions, then acting and assessing and planning again. It may be a little more straightforward for some teams.

The second process presented here is the familiar PDSA cycle referenced in the Transitions Between Settings chapter of this toolkit. The Forum of ESRD Networks' 2010 QAPI toolkit (<http://esrdnetworks.org/mac-toolkits/download>) is another resource for designing a problem-solving process. See an example of a problem-solving process at the end of this chapter.

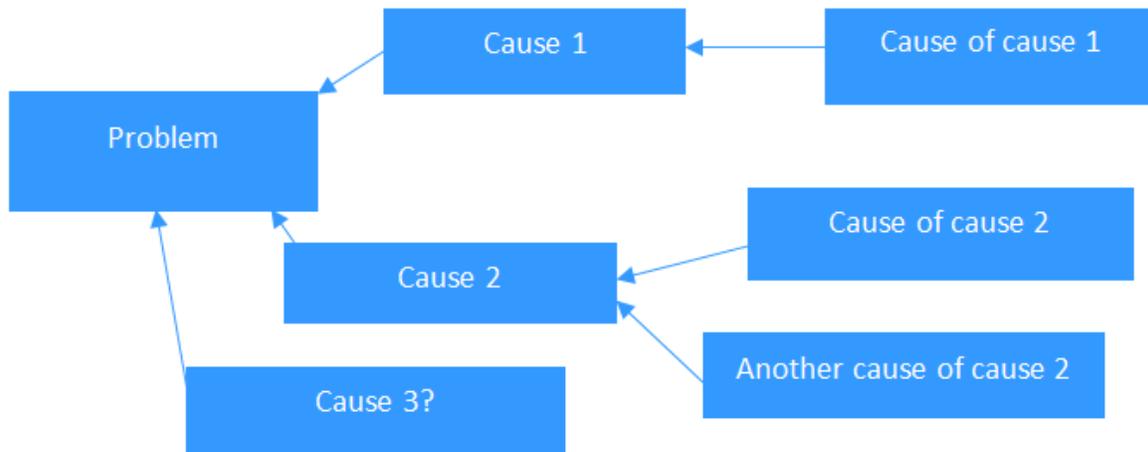
Process 1

- 1) Define the problem. Do not assume the problem is so obvious it does not need to be defined.
 - What is the problem, is it significant, where and when did it happen? You may find that the problem that you define initially needs further refinement. It may be a symptom of a more significant problem.
 - Determine who needs to be on the team to analyze the problem and come up with potential solutions.

Write down the specific problem on the far left of your worksheet, or, better yet, on a sticky note on a bulletin board.

- 2) Discuss the possible causes, as well as the causes of those causes (root cause analysis). Avoid the “blame game”—do not start or end with blaming either a person or an organization or institution. That will not help you find solutions. As you come up with causes, ask “why” for each cause until you can go no further—or it is unnecessary to go further. Look for causes and underlying conditions. Connect the causes. Use evidence (as much as possible) to support the causes. If you do not have evidence for a cause, add a question mark to it. Try to find the one most important cause.
 - A cause may involve people, procedures, equipment, or other resources.
 - It may be helpful to create a flow chart, even if it is incomplete or subject to change, so that all team members can see the sequence of events involved in the problem.
 - Do not start working on solutions until you have exhausted the “whys.”
 - Write down all the ideas, even if you think they are not important.
 - If there are existing processes, describe what they are and consider if they are working.

Write each cause in its own box or on a sticky note to the right of the problem. Add the underlying cause of the first cause as another box. Your chart starts to look like this:



- 3) Identify potential solutions. This is the whole purpose of doing a root cause analysis. There is no “magic bullet” solution, and it may be necessary to put several solutions into place in order to fix the problem. Solutions must meet the criteria that they prevent reoccurrence, **are within your control**, and meet your goals and objectives.
 - Start by proposing solutions to each of the causes that you wrote down. You can add more causes as you go. Don’t get hung up on arguing about solutions. Your team may have as many perspectives as there are team members, so keep an open mind and write them all down. There may not be a solution for every cause.
 - Once you have written down solutions, evaluate each one according to the criteria above. The solution must work, you must have the resources for it, and it must not cause unintended adverse consequences.
 - “Review,” “analyze,” and “investigate” are not solutions! Neither is putting up a warning sign.
 - All the parties must know what the goals and objectives are and what role they have in meeting them.

- 4) Create a plan for creating a solution. It can be broad or narrow in scope.
 - You do not have to solve everything at once.
 - Decide what is most critical for your clinic.
 - Decide what a successful outcome will be.
 - Determine what steps you need to take to improve the outcome using current staff.
 - Assign specific duties to specific staff members.
 - Make sure you can track and trend the results of your actions. A spreadsheet often works best.

- 5) Set a timeline. Evaluate what you have done after the appropriate period of time to see if you have affected the desired change. Create a spreadsheet or log to track your activities and outcomes.

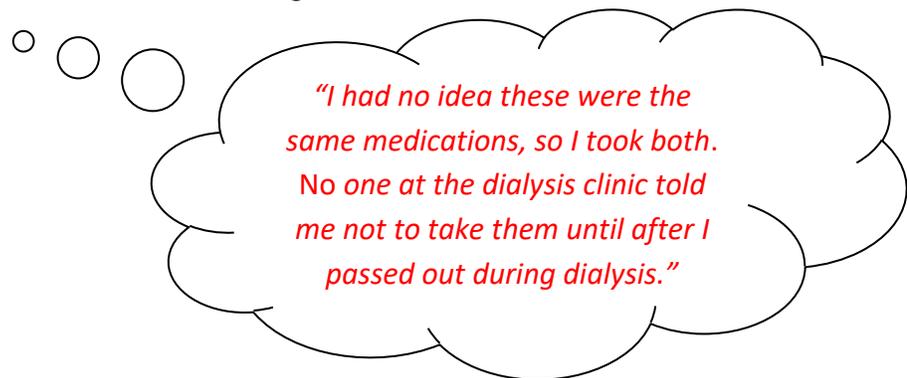
- Review the spreadsheet or log to see how often a particular action occurs (e.g., receiving post-hospitalization dialysis orders).
- Survey staff and patients to see if they are getting enough information about their treatments and what else they need to know.

You may not accomplish your goals 100% of the time, but you need to evaluate whether there has been a change. If there has been, determine what is working and what could be better. If you do not find any improvement, re-evaluate your process and your interventions. The barriers to change may be stronger than your strategies for change, so look for new strategies and interventions.

Process 2

Here is an example of how a team might work through a problem with medication errors following a hospitalization.

Problem: The patient is confused about the discharge medications.



First steps:

Gather real data from relevant cases at your clinic: Have you had other situations in which the patient took the wrong medications following hospital discharge?

Why did these situations happen?

"I think that a doctor told me to tell my nephrologist about my new medication, but I am not sure what he said, or which medicine it was."

- Poor communication with the patient?
- Lack of clear medication reconciliation?
- Lack of clear discharge instructions?
- Lack of appropriate patient/family education?
- Lack of medication assessment when the patient returned from the hospital?

Next steps:

- 1) Evaluate existing processes. Choose three to five cases of recent discharges. Make a complete roadmap of what happened at each step of the discharge medication instruction process.

- Did the processes go well? If not, why not? For example, if the patient was confused about medication instructions, were the medication instructions complete and easy to understand? Was it clear what to stop, what to start, or if a dose was changed?
 - Clearly define what a successful outcome is. This is a critical step. For example, we want to patient to be able to follow the medication instructions and know what the medications are for.
- 2) Evaluate each step. Explore what went wrong with the process. Ideally, make sure all the right people have input. It may take extra effort to include them if they are outside the dialysis clinic. In this example, the patient may not know that a brand name drug in a bottle at home is the same as a new prescription for a generic drug. The EMR may only use generic names that the patient does not recognize. The doctor who discharged the patient did not review the medications with the patient and did not know that the patient would take pills from both bottles.
- 3) Look at each step and ask what could (or should) be done to improve the process using current staff. If the problem arose due to something at the hospital, discuss what to do differently with the hospital transition team and/or patient navigator.
- 4) Determine how to embed each new process under consideration into the current workflow. In this example, this means that you need a process (and policy) for reviewing the discharge medications. You need to know whether the patient is using the list from the hospital. You may have to require the patient to bring in all of his or her medication containers following a hospital discharge so that the RN can check them. This should include medications that the patient is no longer taking.
- 5) Define the exact steps of the new process. Define exactly who will be responsible and factor that into the workflow. Learn from others, see what the literature has to offer, and see if other clinics in your organization have processes that work.
- 6) Make a detailed "hardwired" script for each new process. For example, the process may be that the RN first reviews and records the medication list. He or she then either sends it to the practitioner or flags it for attention at the next practitioner visit.
- 7) Decide how you are going to track the outcomes of your new processes. Determine a timeline. Decide what information you need to know to determine if your solutions are working.
 - Record and trend the data. Determine if the outcomes are improving. In this example, ask patients who were recently discharged from the hospital if they know what medications to take and which ones they are not supposed to take. Record whether they think they do or do not know. Record whether they are right.

Simplified example of the problem-solving process



APPENDIX

Online Resources for Professionals

First Dialysis Treatment

“Transitioning from CKD to RRT” (<http://ispd.org/NAC/wp-content/uploads/2010/11/Transitioning-from-CKD-to-RRT-Bernardini-April-2011-Notes.pdf>): This PowerPoint slide set is about the value of education regarding CKD and ESRD when the eGFR is less than 30 ml/min.

“Discussions of Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study” (<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3626427/pdf/nihms451204.pdf>): This *American Journal of Kidney Diseases* article by J. Schell et al. (AJKD 2012, 59(4):495-503) describes patient responses to the diagnosis of kidney failure, the fact that they feel unprepared for living with dialysis and are uncertain of what will happen to them. It also describes the struggles of nephrologists to explain the complexity of the disease, their often lack of control over disease progression, and their discomfort with discussing the future.

“Patient perspectives on informed decision-making surrounding dialysis initiation” (<http://ndt.oxfordjournals.org/content/28/11/2815.long>): This *Nephrology, Dialysis and Transplantation* article by M. K. Song et al. (NDT 2013, 28(11):2815-2823) describes patient perspectives on preparation for dialysis. While most patients felt that their physicians were trying to communicate well, there were communication gaps regarding the impact of renal replacement therapy on quality of life, survival, disease management, etc.

“Goal-Oriented Patient Care—An Alternative Health Outcomes Paradigm” (<http://www.nejm.org/doi/full/10.1056/NEJMp1113631>): This *New England Journal of Medicine* article by D. Reuben and M. Tinetti (NEJM 2012, 366:777-779) discusses the importance of focusing on the goals of patients with complex chronic diseases rather than a narrow focus on disease management.

“Learning to Live with Kidney Failure: A Patient’s Perspective” (<http://www.kidneypatientnews.org/ckd/amin.php>): This resource is a well-written article by patient Yusuf Amin, with advice for others about approaching dialysis.

Peer Mentoring

Forum of ESRD Network’s Quality Conference Webinar Peer Mentoring Resource List
<http://esrdnetworks.org/education/quality-conference/quality-conference-2016-2017/webinar-3-slides-recording-q-a-document-and-additional-resources/resource-peer-mentoring-resources/view>

Modality Change

“The End-Stage Renal Disease Patient’s Life Plan: Extending Survival by Managing Health”

(http://www.medscape.com/viewarticle/559524_2): This resource is a talk given by Dr. Martin Schreiber (2007) addressing the transitions between treatment modalities and the need to plan for them, as well as the need to discuss a life plan including survival and comorbidity accountability. Site is free but does require registration.

“Health-related and psychosocial concerns about transplantation among patients initiating dialysis”

(<http://cjasn.asnjournals.org/content/early/2014/09/03/CJN.03310414.abstract>): This *Clinical Journal of the American Society of Nephrology* article by M. Salter et al. (CJASN 2014, 9:1940-1948) discusses how elderly and female patients were often unwilling to pursue transplant due to feeling that they were doing well on dialysis and reluctance to ask for a donation. This is the abstract; the full paper is available to subscribers or for a fee.

“Return to dialysis after kidney transplantation: Which would be the best way?”

(<http://www.nature.com/ki/journal/v61/n80s/full/4493031a.html>): This *Kidney International* article by M. Arias et al. (KI 2002, 61:S85-S88) discusses how complications and hospitalizations after initiation of dialysis following transplant loss was higher than for incident kidney failure patients initiating dialysis. The authors argue for earlier referral to dialysis when the transplant is failing.

“Coming back to dialysis after kidney transplant failure”

(<http://ndt.oxfordjournals.org/content/23/9/2738.full>): This *Nephrology, Dialysis and Transplantation* article by P. Messa et al. (NDT 2008, 23:2738-2742) discusses the challenges of determining when to resume dialysis and how to manage the transition.

“Clinical outcomes after failed renal transplantation—does dialysis modality matter?”

(<http://www.ncbi.nlm.nih.gov/pubmed/18533967>): This *Seminars in Dialysis* article by J. Perl et al. (Semin Dial 2008, 21(3): 239-244) discusses how the impact of dialysis modality on the survival of patients following transplant failure is unknown.

“Reduced survival and quality of life following return to dialysis after transplant failure: the Dialysis

Outcomes and Practice Patterns Study” (<http://www.ncbi.nlm.nih.gov/pubmed/23028105>): This is a *Nephrology, Dialysis and Transplantation* article by J. Perl et al. (NDT 2012, 27: 4464-4472). This is the abstract; the full paper is available to subscribers or for a fee.

“Initial vascular access type in patients with a failed renal transplant”

(<http://cjasn.asnjournals.org/content/9/7/1225.abstract?sid=ffbb1bc2-4aea-4208-85ec-58cfaf0b7762>): This *Clinical Journal of the American Society of Nephrology* article by M. Chan et al. (CJASN 2014, 9:1225-1231) discusses patient access use when returning to dialysis.

“Kidney transplant failure: Failing kidneys, failing care?”

(<http://cjasn.asnjournals.org/content/9/7/1153.full>): This *Clinical Journal of the American Society of Nephrology* article by J. Perl (CJASN 9:1153-1155) is an editorial that examines the reasons for the high rate of central venous catheter usage when patients start dialysis following transplant failure.

Supportive and Palliative Care

“Transitions in the Lives of patients with End Stage Renal Disease: a cause of suffering and an opportunity for healing” (<http://www.mcgill.ca/files/wholepersoncare/HutchinsonESRDTransitions.pdf>): This thoughtful *Palliative Medicine* article by T. Hutchinson (Pall Med 2005, 19:270-277), from the Division of Palliative Medicine at the McGill University Health Centre, discusses coping with difficult and challenging transitions throughout one’s life with ESRD. It is not just about end of life transitions.

Renal Physicians Association (RPA) iOS app (<https://itunes.apple.com/us/app/id843971920?mt=8>): This free app (released April 2014) is for improving dialysis decisions and quality of life for kidney patients and includes a prognosis calculator for dialysis patients and links to Web-based resources.

“Transitions Conversations Help Bridge Gaps in Care”

(http://www.oncologyfellowadvisor.com/ViewArticle.aspx?d=Fellowship%2bTraining&d_id=425&i=January+2012&i_id=861&a_id=19932): This informative article from Oncology Fellow Advisor (site commercially sponsored by Lilly) focuses on communication in the care of cancer patients who transition from treatment to palliation and includes tips on improving transition conversations. It is useful for kidney care.

“Facilitating Advance Care Planning for Patients with End-Stage Renal Disease: The Patient Perspective”

(<http://cjasn.asnjournals.org/content/1/5/1023.long>): This *Clinical Journal of the American Society of Nephrology* article by S. Davidson (CJASN 2006, 1(5):1023-1028) includes patient interviews on end of life discussions and talks about how patients rely on their physicians to assist them with advanced care planning, but find that their health teams often did not or would not engage in those discussions.

“NephroTalk: Communication Tools to Enhance Patient-Centered Care”

(<http://onlinelibrary.wiley.com/doi/10.1111/sdi.12017/abstract>): This *Seminars in Dialysis* article by J. Schell and R. Arnold (Semin in Dial 2012, 25:611-616) describes sample physician/patient discussions about goals, particularly end of life decision making. This is the abstract; the full paper is available to subscribers or non-subscribers for a fee.

Renal Physicians Association Shared Decision Making in the Appropriate Initiation of and Withdrawal from Dialysis (Second Edition) (<http://www.renalmd.org/catalogue-item.aspx?id=682>): This resource includes clinical practice guidelines. There are links for free download of the Recommendations Summary and the Toolkit Section. The full downloadable copy of the guidelines can be ordered free from the link.

Transitions between Settings

Dialysis-specific

Care Transitions (<http://www.therenalnetwork.org/qi/caretransitions.html>): This toolkit from ESRD Network 9/10 includes sample templates of confidentiality agreements and transfer summaries that can be downloaded and adapted.

Not Dialysis-specific

National Transitions of Care Coalition (<http://www.ntocc.org/Home.aspx>): This website has information, tools, and templates for providers and for patients and their families. Individuals and organizations can join free.

Care Transitions Program (<http://caretransitions.org/>): This is a proprietary program under the direction of Dr. Eric Coleman that focuses on using a Transitions Coach. The website has free downloadable tools, including a personal health record and medication discrepancy tool.

Project BOOST Toolkit

(http://www.hospitalmedicine.org/ResourceRoomRedesign/RR_CareTransitions/html_CC/Implementation.cfm): This toolkit is a product of the Society of Hospital Medicine aimed at hospital interventions to reduce readmissions. It is long, but don't worry—has many blank pages. The appendix has many good references. It contains a Risk Assessment Tool (page 49)—the 8 Ps (problem medications, psychological, principal diagnosis, polypharmacy, poor health literacy, patient support, prior hospitalizations in the last 6 months, palliative care)—and a discharge checklist (page 51) that may be useful for dialysis clinics to assess what was done at discharge.

Project RED (Re-Engineered Discharge) (<https://www.bu.edu/fammed/projectred/>): This clearly written and well-organized resource from the Boston University Medical Center, supported by grants from AHRQ, NIH, NHBLI, Patient Centered Outcomes Research Institute, and others, has very specific steps and interventions regarding hospital discharge and includes advice regarding diverse populations and how to integrate family into the discharge process.

INTERACT (<http://interact2.net/index.aspx>): This quality improvement program is aimed at skilled nursing facilities and focuses on interventions to reduce hospitalizations and assist with root cause analysis of resident hospitalizations. Some of the tools are modifiable for use by dialysis facilities. Tools for home health care and for Accountable Care Organizations and health systems are pending.

Articles and Other General Information

Dialysis-specific

“Physician Visits and 30 day hospital readmissions in patients receiving hemodialysis”

(<http://jasn.asnjournals.org/content/25/9/2079.abstract>): This *Journal of the American Society of Nephrology* article by K. Erickson et al. (JASN 2014, 25:2079-2087) discusses how more frequent physician visits and closer outpatient monitoring following hospital discharge is associated with fewer 30-day readmissions. The full text is available by subscription to JASN or pay per article for nonsubscribers.

“Reducing Avoidable Rehospitalization in ESRD: A Shared Accountability”

(<http://jasn.asnjournals.org/content/25/9/1891.full.pdf+html>): This *Journal of the American Society of Nephrology* article by R. Hakim and A. Collins (JASN 2014, 25:1891-1893) is an editorial on reducing avoidable re-hospitalizations.

“Utilization of Acute Care among patients with ESRD discharged home from skilled Nursing Facilities”

(<http://cjasn.asnjournals.org/content/10/3/428.abstract>): This *Clinical Journal of the American Society of Nephrology* article by F. Hall et al. (CJASN 2015, 10(3):428-434) discusses how home health use was associated with a lower rate of acute care use. The full text is available by subscription to CJASN or pay per article for nonsubscribers.

“The CMO Initiative: Improving the continuity of care for dialysis patients”

(<http://www.nephrologynews.com/the-cmo-initiative-improving-the-continuity-of-care-for-dialysis-patients/>): This *Nephrology New and Issues* report prepared by P. DeOreo (NNI January 2014) discusses the recommendations from dialysis company chief medical officers to improve continuity of care between outside settings and the dialysis clinic.

“The Transition to ESRD” (http://www.usrds.org/2009/view/v1_07_transition.asp): This 2009 report from the USRDS describes the frequency of PCP and nephrologist visits in the quarters prior to starting ESRD treatment, incident fistula rates, numbers of patients evaluated for anemia, calcium/phosphorus abnormalities, medication use, etc.

“Handoff Communication Between Hospital and Outpatient Dialysis Units at Patient Discharge: A Qualitative Study”

(<http://www.healthcareinformed.com/ie/downloads/Handoff%20Communication%20Between%20Hospital%20and%20Outpatient%20Dialysis%20Units%20at%20Patient%20Discharge.pdf>): This resource from the Joint Commission *Journal on Quality and Patient Safety* by K. Reilly et al. (JQPS 2013, 39(2):70-76) studies and discusses poor “hand-off” communications between practitioners and providers. The abstract is available at <http://www.ncbi.nlm.nih.gov/pubmed/23427478>.

“Evaluation of deficiencies in current discharge summaries for dialysis patients in Canada”

(<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3333802/>): This *Journal of Multidisciplinary Healthcare* article by Z. Harel et al. (JMHS 2012, 5:77-84) discusses how most dialysis center medical directors felt that hospital discharge summaries are inadequate. Critical information such as antibiotics, modifications to dialysis access, and changes in the target weight and dialysis prescription information was often missing.

Not Dialysis-specific

“Transition of care consensus policy statement: American College of Physicians, Society of General Internal Medicine, Society of Hospital Medicine, American Geriatrics Society, American College of Emergency Physicians, and Society of Academic Emergency Medicine”

(<http://onlinelibrary.wiley.com/doi/10.1002/jhm.510/full>): This resource from the *Journal of Hospital Medicine* is a consensus statement by V. Snow et al. (J Hosp Med 2009, 4:364-370) regarding transitions between inpatient and outpatient settings, including the data elements that should be communicated.

Always Events (<http://pickerinstitute.org/publications-and-resources/>): This section of the Picker Institute site regards transitions that occur between and within organizations. Providers can identify “always events,” which are aspects of the patient experience that are so important that providers should always get them right.

“Meet Margaret and Pat” (<http://alwaysevents.pickerinstitute.org/wp-content/uploads/2011/11/AE-13-Quality-Partners-Power-Point.pdf>): This PowerPoint presentation from the Picker Institute highlights the disconnect between what is being planned in the hospital and what the patient’s caregiver is experiencing. It presents side-by-side bullet points detailing the day-by-day experiences of an elderly patient and her family caregiver as she transitions from home, to the hospital, then to an SNF, and eventually back home.

“Transition in Care 2.0: An Action Agenda” (<http://www.uhfnyc.org/assets/1095>): This statement from the United Hospital Fund, largely aimed at hospitals, outlines what is required for improving transition between settings. Also see this blog that summarizes the recommendations:

<http://www.caregiving.com/2013/05/ten-recommendations-to-improve-care-transitions/>.

“Association Between Quality Improvement for Care Transition in Communities and Rehospitalizations Among Medicare Beneficiaries”

(<http://jama.jamanetwork.com/article.aspx?articleid=1558278#METHODS>): This *Journal of the American Medical Association* article by J. Brock et al. (JAMA 2013, 309(4):381-391) studies Quality Improvement Organization (QIO) transitions with intervention and nonintervention groups. QIOs assisted institutions with quality improvement processes using multiple interventions. The authors found minimal difference in hospitalization rates between intervention and nonintervention groups and no difference in readmission rates.

DCPatient Blog (<http://www.dcpatient.us/2011/10/a-patients-perspective-on-improving-care-transitions/>): This blog belongs to a very articulate lawyer and liver transplant patient, DCPatient.

“Seamless Care: Safe Patient Transitions from Hospital to Home”

(<http://www.ncbi.nlm.nih.gov/books/NBK20459/>): This selection from the book *Advances in Public Safety from the Agency for Healthcare Research and Quality* describes the common patient and organizational factors that lead to readmissions. The authors suggest that targeting high-risk patients and improving communications can prevent some readmissions.

Discharge Protocol (<http://www.ihl.org/resources/Pages/Tools/SMARTDischargeProtocol.aspx>): These instructions and template from the Anne Arundel Medical Center in Annapolis, MD, focus on communications with the patient.

“Hospital Readmission among Participants in a Transitional Care program”

(http://www.ajmc.com/publications/issue/2010/2010-10-vol16-n10/AJMC_10octOsmAhmed778to783):

This article from 2010 reviews retrospective data from a large health care company (Optum) and finds that patients enrolled in a transitional case management program had a 30-day 13% readmission rate compared to 36% readmission rate by non-enrollees. The primary intervention was post-discharge, telephonic, in-depth patient follow-up by case managers. Case managers evaluated gaps in care, patient condition, discharge instructions, and adherence to care plans. They contacted the physician(s) as needed and identified other resources that patients needed.

Pediatric Transition Resources

Transition from Pediatric- to Adult-focused Clinics

“Transition Care for Children with Special Health Needs”

(<http://www.effectivehealthcare.ahrq.gov/ehc/products/546/1920/children-special-needs-transition-report-140617.pdf>): This technical brief from the Agency for Health Care Research and Quality (AHRQ) is a long, but readable report on transitions from 2014 that includes data from studies of pediatric kidney transplant patients who participated in transition programs (Table 4 on page 34). Table C-2 (page C-2 of Appendix C) lists Federal and State-level transition resources and programs.

“The health care transition research consortium health care transition model: A framework for research and practice”

(<http://iospress.metapress.com/content/qhg1q073324x4642/?p=eb8699ae12e64a488eb424d1755e6e93&pi=1>): This *Journal of Pediatric Rehabilitative Medicine* article by C. Betz et al. (J Ped Rehab Med 2014, 7:3-15) describes a health care transition theoretical model developed by the international Health Care Transition Research Consortium. The link is for an abstract.

“Transition of the adolescent patient to the adult clinic”

(http://www.pdiconnect.com/content/29/Supplement_2/S180.full): This succinct *Peritoneal Dialysis International* article by H. Alpay (Perit Dial Int 2009, 29:S180-182) outlines the transition process, as well as potential barriers.

“Moving On: Improving the Transition from Pediatric to Adult Care”

(http://journals.lww.com/nephrologytimes/Fulltext/2009/05000/Moving_On_Improving_the_Transition_from_Pediatric.6.aspx): This brief *Nephrology Times* article by M. Hogan (NT 2009, 2(5):11-15) features interviews of pediatric nephrologists at the National Kidney Foundation Spring Clinical Meetings 2009.

“Health Care Transition: Destinations Unknown”

(http://pediatrics.aappublications.org/content/110/Supplement_3/1307.full.pdf): This *Pediatrics* article by J. Reiss and R. Gibson (Ped 2002, 110:1307-1314) reviews the development and evaluation of health care transition policy over the previous decades.

“Transition from Pediatric to Adult Care: Bridging the Gaps or Passing the Buck?”

(<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1718076/pdf/v081p00271.pdf>): This *Archives of Diseases of Childhood* article by R. Viner (Arch Dis Child 1999, 81:271-275) discusses the challenges of the transition and best practice recommendations for a successful transition.

Pediatric Patient Challenges

“Duration of Chronic Kidney Disease Reduces Attention and Executive Function in Pediatric Patients”

(http://www.medscape.com/viewarticle/843713?nlid=81899_521&src=wnl_edit_medp_neph&spon=44): This is a *Kidney International* article by S. Mendley et al. (KI 2015, 87(4):800-806).

“An Overview of Minors’ Consent Law”

(http://www.guttmacher.org/statecenter/spibs/spib_OMCL.pdf): A resource from the Guttmacher Institute State Policies in Brief. The site appears to be updated frequently.

Pediatric Transition Programs

STARx Program (<http://www.med.unc.edu/pediatrics/transition>): A collection of self-management and transition readiness assessment tools from the University of North Carolina to prepare pediatric patients to be successful in the adult world, available in English and Spanish, with tools specific to kidney disease. The STARx Founder and Director is a pediatric nephrologist, Dr. Maria Ferris.

Got Transition (<http://www.gottransition.org/>): This collaborative product of the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health has comprehensive information about transition for youth, families, and service providers. The “for providers” section contains general resources, information related to best practices, and resources specifically about the ‘six core elements

of transition,' presented in English and Spanish, with sample templates, checklists, and letters. It is not specific to kidney disease.

Good 2 Go Transitions Program (<http://www.sickkids.ca/good2go/>): This Toronto SickKids Hospital and Centers of Excellence resource includes transitions guidelines, transition readiness checklists, sample posters, word search games for adolescents using medications, health passport, information for patients about sexual health and substance use, and templates. It is not specific to kidney disease.

Florida Health and Transition Services (<http://www.floridahats.org/>): This website includes planning guides, patient informational material, online training programs, checklists, and other resources for patients, families, and healthcare professionals, presented in English and Spanish. It is not specific to kidney disease.

OnTrac Program (<http://ontracbc.ca/>): A program from British Columbia, Canada, that has toolboxes for young adults and families to help plan, prepare and transfer into adulthood and adult health care. It is not specific to kidney disease.

Adolescent Health Transition Project (<http://depts.washington.edu/healthtr/about.html>): An excellent source from the Center on Human Development and Disability at the University of Washington for patient handouts, booklets, forms and checklists related to preparing for transitions within health care and school, with a focus on diabetes. It has several videos of panel discussions by medical experts, family members and patients. The site is not being updated due to lack of funding.

Resources for Families

“Transition of Care from Pediatric to Adult Clinics”

(<http://archpedi.jamanetwork.com/article.aspx?articleid=1703907>): This resource is a Journal of the American Medical Association (JAMA) Pediatrics article by M.A. Moreno, MD, that provides advice on transitions of care directed at the parents of transitioning adolescents or young adults.

Additional Pediatric Tools and Templates

Healthy and Ready to Work National Resource Center (<http://syntiro.org/hrtw/tools/index.html>): This site provides Web-based tools for use by youth, families, and healthcare providers, as well as state and local agencies to achieve successful health transitions.

“University of California at San Francisco Transitioning Adolescent Patients (TAP) from Pediatric to Adult Care” (<http://cgp.pickerinstitute.org/?p=1478>): This project assessed transition readiness of a patient group in a rheumatology clinic. The site contains a “Lupus Health Passport” that could be used as a model for other health condition passports.

Care Coordination Letter (): A pdf copy of the RPA and ASPN care coordination letter is included in this toolkit, courtesy of the Renal Physicians Association. The Renal Physicians Association (<http://www.renalmd.org/>) and the American Society of Pediatric Nephrology (<http://aspneph.com/>) sites have web-based templates with drop-down menus for care coordination communications between pediatric and adult providers/practitioners, available to members.

Other Resources

Health Literacy and Cultural Awareness

Minnesota Health Literacy Partnership (<http://healthliteracymn.org/resources/presentations-and-training>): A resource for presentations and training materials about health literacy.

Cultural Sensitivity: a pocket guide for Health Care Professionals (Second Edition, 2012; not available online): This guide by G. Galanti, PhD, with forward by M. Woods, MD, addresses values, world view, communication, family/gender issues, and “cradle to grave” beliefs and traditions for each culture. This guide is available for purchase through the Joint Commission Resources (www.jcrinc.com) for \$39/copy.

Quality Improvement

“Forum of ESRD Networks Quality Assessment and Performance Improvement Toolkit” (<http://esrdnetworks.org/mac-toolkits/download/download-toolkit-and-write-able-forms-qapi-toolkit/qapi-toolkit/view>): This toolkit (2010) includes sample templates for quality improvement projects.

Apollo Root Cause Analysis: A New Way of Thinking (book; not available online): An Apollonian Publications (2008) resource by Dean L. Gano about another approach to quality improvement activities.

Communications and the “Culture” of the Clinic

“6 Effective Verbal Intervention Strategies” (<http://www.crisisprevention.com/Blog/May-2013/6-Effective-Verbal-Intervention-Strategies>): This commercial site provides techniques and resources for verbal crisis intervention.

“TeamSTEPPS: National implementation plan” (<http://teamstepps.ahrq.gov/aboutnationalIP.htm>): This Agency for Healthcare Research and Quality (AHRQ) evidence-based teamwork system is used by hospitals and other healthcare providers to train front line providers and requires registration by an institution.

“Patient safety and the ‘Just Culture’”

(http://www.health.ny.gov/professionals/patients/patient_safety/conference/2007/docs/patient_safety_and_the_just_culture.pdf): This PowerPoint presentation by C. Marx (2007) discusses the concept of a

“just culture,” which is one in which it is recognized that we must balance accountability and the possibility of human error.

Online Educational Resources for Patients

Treatment Choices

My Dialysis Choice (www.mydialysischoice.org): Developed by the non-profit Medical Education Institute, this tool helps patients choose the treatments that are right for them, based on their values and goals.

The Kidney School (<http://kidneyschool.org/>): This site provides learning modules about kidney disease and ESRD treatments and includes rights and responsibilities and advice to patients about how to deal with difficult situations, such as filing complaints or grievances.

Life Options (<http://lifeoptions.org/>): Developed by the non-profit Medical Education Institute, this program has multiple free and other resources for patients and providers, including the Life Options Rehabilitation Program, Kidney School, Home Dialysis Central, and the Core Curriculum for the Dialysis Technician. The program has an emphasis on patient self-management.

When I Should Start Dialysis (<http://www.uwhealth.org/health/topic/decisionpoint/kidney-failure-when-should-i-start-dialysis/abo2705.html>): An interactive site created by the University of Wisconsin to help patients understand when it is time to start dialysis.

Approaching Dialysis

“Learning to Live with Kidney Failure: A Patient’s Perspective” (<http://www.kidneypatientnews.org/ckd/amin.php>): This resource is a well-written article by patient Yusuf Amin, with advice for others about approaching dialysis.

Supportive Care

Coalition for Supportive Care of Kidney Patients (<http://kidneysupportivecare.org>): This website has information and resources for patients and for professionals regarding supportive care including palliative and hospice care, as well as pain management and advance care planning.

Hospitalization

Dialysis: Five ways to be active in your care at the hospital (http://www.jointcommission.org/topics/speak_up_five_ways_to_be_active_in_your_care.aspx): This brochure is from the Joint Commission and is available in English and Spanish.

Transitions of Care (http://www.caretransitions.org/caregiver_resources.asp): This resource from the Eric Coleman Transitions Program for patients and caregivers includes tips on medication management, watching for “red flags” that one’s medical condition is worsening, and other topics. It also has links to

templates for a personal health record and a hospital discharge checklist for patients to use. This resource is not specifically for kidney patients.

Hospital Discharge Checklist (<http://www.medicare.gov/Publications/Pubs/pdf/11376.pdf>): This resource is a checklist provided by Medicare and is not specifically for kidney patients. This link opens a PDF.

Managing Medications

Medication List (http://www.ntocc.org/Portals/0/PDF/Resources/My_Medicine_List.pdf): This resource is a medication list template from the National Transitions of Care Coalition. This link opens a PDF.

My Medications (<http://www.ama-assn.org/ama/pub/about-ama/apps/my-medications.page>): This resource has information on the “My Medications” smartphone app that holds patients’ medications and other personal medical information, available for free through the iTunes store.

My Medicine Record

(<http://www.fda.gov/downloads/aboutfda/reportsmanualsforms/forms/ucm095018.pdf>): This resource has information on the downloadable medication record from the Federal Food and Drug Administration (FDA). This link opens a PDF.

Pediatric Transitions

“Transition of Care from Pediatric to Adult Clinics”

(<http://archpedi.jamanetwork.com/article.aspx?articleid=1703907>): This resource is a Journal of the American Medical Association (JAMA) Pediatrics article by M.A. Moreno, MD, that provides advice on transitions of care directed at the parents of transitioning adolescents or young adults.

General Resources

American Association of Kidney Patients (<https://www.aakp.org/>): This website has patients with many resources for education and support.

National Kidney Foundation (<https://www.kidney.org/>): This website has educational resources for patients.

National Kidney Disease Education (<http://nkdep.nih.gov/>): This program, developed by the National Institutes of Health’s Institute of Diabetes and Digestive and Kidney Diseases, has educational resources for patients.

SAMPLE TEMPLATES

Post-hospitalization Checklist

DaVita post hospitalization protocol, April 2015

Reproduced with permission from Dr. Stephen McMurray, DaVita Health Care Partners

- 1) Assess/Adjust Target Weight First Treatment Back from the Hospital
- 2) Follow the DaVita FluidWise Fluid Management Clinical Pathway for Post-Hospitalized Patients
- 3) Review New Medications
- 4) Review Discontinued Medications
- 5) Review Modified Medications
- 6) Note Change to Heparinization (ICHD/HHD)
- 7) Note Change to IV/IP Antibiotics
- 8) Note Any New/Protocol Labs Required Upon Readmission
- 9) Record any Follow-Up from Hospital
- 10) Facilitate Provider/Specialist Appointments or Follow-Up
- 11) Facilitate Durable Medical Equipment and Home Health Referrals
- 12) Confirm Advance Directives in Place and/or Update
- 13) Facilitate Patient/Caregiver Education
- 14) Review Changes in Treatment Plan with IDT
- 15) Obtain and Record Blood Cultures Drawn During Hospital Admission

Dialysis Unit to Hospital Transfer Summary

{Your logo here}

Dialysis Unit to Hospital Transfer Summary

Patient Information		Reason for Admission	
Name / ID: _____ DOB: / /		_____	
Chronic Dialysis Unit Name: _____		_____	
Primary Renal DX: _____		_____	
Nephrologist: _____		Hospital Name: _____	
Unit Phone: _____ Nephrologist Phone: _____		Date of Admission: / /	
Hepatitis B		Code Status	
Antigen: _____ Antibody: _____		<input type="checkbox"/> Full <input type="checkbox"/> DNR	
Date: / /		Other Instructions: _____	
Allergies: _____		Competent to Sign Consents	
		<input type="checkbox"/> Yes <input type="checkbox"/> No	
Current Vascular Access		Vascular Access Infection	
PRIMARY SECONDARY (if any)		(within last 30 days):	
<input type="checkbox"/> CATH <input type="checkbox"/> CATH		<input type="checkbox"/> NO <input type="checkbox"/> YES	
<input type="checkbox"/> AVF <input type="checkbox"/> AVF		Positive Blood cultures:	
<input type="checkbox"/> AVG <input type="checkbox"/> AVG		<input type="checkbox"/> NO <input type="checkbox"/> YES	
<input type="checkbox"/> Other <input type="checkbox"/> Other		If Yes- name antibiotic(s) given:	
Access Location: _____		_____	
Access Surgeon: _____		Organism type: _____	
Needle Size: _____			
Average bleeding time: _____			
Buttonhole cannulation:			
<input type="checkbox"/> NO <input type="checkbox"/> YES, Details: _____			
Dialysis Prescription		Heparin:	
TX per week: _____ Duration: _____		Load: _____	
Schedule: _____		Hourly: _____	
Dialysate = Na: _____ K: _____ Ca: _____		Mid Tx bolus: _____	
Bicarb setting: _____		Dialyzer: _____	
DFR rate: _____ BFR Rate: _____		Treatment tolerance:	
Dry Weight: _____		<input type="checkbox"/> Well	
		<input type="checkbox"/> Fair	
		<input type="checkbox"/> Poor	
		Details: _____	
Anemia Management		IV IRON Therapy:	
ESA's given during the admission:		<input type="checkbox"/> Venofer [®] <input type="checkbox"/> Ferrlecit [®]	
<input type="checkbox"/> None		<input type="checkbox"/> Feraheme [®] <input type="checkbox"/> Infed [®]	
<input type="checkbox"/> Epogen [®] <input type="checkbox"/> Aranesp [®] <input type="checkbox"/> Procrit [®]		<input type="checkbox"/> Dexferrum [®] <input type="checkbox"/> Other _____	
Last Dose/Date Received: _____		Last Dose/Date Received: _____	
_____ / /		_____ / /	
		Any RBC transfusions: <input type="checkbox"/> NO <input type="checkbox"/> YES	
		date(s) _____	
		HGB prior to transfusion(s) _____ gm/dL	
		Most recent:	
		Hgb: _____ Date: / /	
		Hct: _____ Date: / /	
Dietary Order			
Na: _____ K: _____ Phos: _____		Fluid restriction: _____	
Protein: _____ Calories: _____			
Routine Dialysis Medications			

Attachments			
<input type="checkbox"/> Last 3 HD flow-sheets <input type="checkbox"/> Medication list <input type="checkbox"/> Care Plan <input type="checkbox"/> Other (list): _____			

This form completed by _____ Please print above (Name) _____ (Phone) _____ (Date)

Hospital to Dialysis Unit Transfer Summary

{Your logo here}

Hospital to Dialysis Unit Transfer Summary

Patient Information		Hospital Information	
Name / ID: _____ DOB: / /		Hospital: _____	
Primary Renal DX: _____		Unit: _____	
Hepatitis B Antigen: _____ Antibody: _____ Date: / /		Phone: _____	
Code Status <input type="checkbox"/> Full <input type="checkbox"/> DNR Other Instructions: _____		Admission Date: / /	
Competent to Sign Consents <input type="checkbox"/> Yes <input type="checkbox"/> No		Inpatient Attending Nephrologist(s): _____	
Outpatient Dialysis Unit Accepting Transfer Facility: _____ Phone: _____ Contact: _____		Discharge Date: / /	
		Discharging Physician: _____	
Current Vascular Access <input type="checkbox"/> Tunneled catheter <input type="checkbox"/> AVF <input type="checkbox"/> AVG <input type="checkbox"/> Other _____		Vascular access infection: <input type="checkbox"/> No <input type="checkbox"/> Yes Positive blood cultures: <input type="checkbox"/> No <input type="checkbox"/> Yes – Name of antibiotic(s) given: _____ Organism Type: _____	
Any changes this admission: <input type="checkbox"/> Clotting <input type="checkbox"/> Declotting <input type="checkbox"/> Revision <input type="checkbox"/> New Placement – Please describe: _____			
Anemia Management ESA's given during the admission: <input type="checkbox"/> None <input type="checkbox"/> Epogen® <input type="checkbox"/> Aranesp® <input type="checkbox"/> Procrit® Last Dose/Date Received: / /		Any RBC transfusions: <input type="checkbox"/> NO <input type="checkbox"/> YES date(s) _____ HGB prior to transfusion(s) _____ gm/dL Most recent: Hgb: _____ Date: / / Hct: _____ Date: / /	
IV IRON Therapy: <input type="checkbox"/> Venofer® <input type="checkbox"/> Ferrlecit® <input type="checkbox"/> Feraheme® <input type="checkbox"/> Infed® <input type="checkbox"/> Dexferrum® <input type="checkbox"/> Other _____ Last Dose/Date Received: / /			
Miscellaneous Date of last HD prior to discharge: / / Changes to EDW: _____ Treated for other infections: (list) _____		Medication changes: _____ _____ _____ Other: _____	
Co-morbid Conditions - Did the patient receive treatment during this admission for the following conditions? <input type="checkbox"/> Pericarditis <input type="checkbox"/> Bacterial Pneumonia <input type="checkbox"/> GI Bleeding			
Discharge Dialysis Prescription/Orders			
TX per week: _____ Duration: _____ Schedule: _____		Heparin: _____ Treatment tolerance: _____	
Dialysate Na: _____ K: _____ Ca: _____		Load: _____ <input type="checkbox"/> Well	
Bicarb setting: _____		Hourly: _____ <input type="checkbox"/> Fair	
DFR rate: _____ BFR Rate: _____ Dry Weight: _____		Mid Tx bolus: _____ <input type="checkbox"/> Poor	
		Dialyzer: _____ Details: _____	
Discharge Instructions			
<input type="checkbox"/> Telephone report to the Chronic HD unit <input type="checkbox"/> Report any changes in access placement or function <input type="checkbox"/> Verify that transportation arrangements have been made through Social Service		<input type="checkbox"/> Fax following Medical Records: <input type="checkbox"/> Last three HD treatment sheets <input type="checkbox"/> Medication list <input type="checkbox"/> Recent lab work-(Chemistries, CBC, Cultures) <input type="checkbox"/> H&P, Nephrology consult, Radiology/Scan reports, Discharge Notes	

This form completed by _____ Please print above (Name) _____ (Phone) _____ (Date)

Pediatric to Adult Care Coordination Letters

These care coordination letters are designed to be sent by a pediatric nephrologist or pediatrician to an internist specializing in nephrology care to aid in the successful transition from pediatric to adult nephrology care. The letters are presented in two stages, one prepared to initiate transitioning proceedings to be sent well in advance of a pediatric patient's transfer to adult nephrology care and the other to complete the transition to be sent when transfer is imminent. These letters are meant to serve the following purposes:

- Help establish effective communication between pediatric and adult nephrology physicians
- Transmit the patient's relevant clinical, social, and insurance information effectively and efficiently
- Serve as a reminder regarding family involvement in pediatric kidney disease care

Pointers for effective use of this tool:

- You can use the letter as provided, or format it with your own letterhead and personalize it by typing in the name of the addressee, the patient's name, dates, etc. (Please use the MS-Word version for this purpose.)
- If you generally dictate your own personalized letters, you may want to use the bulleted checklist that will simply serve as a guide for your own letter.
- If you prefer to use a web-based tool with drop-down menus to select various options, a web version of the letter is available at www.renalmd.org/ncap or <http://www.aspneph.com/> (insert actual link when available).
- You may want to include other materials important to the successful transitioning of care including growth charts, resource list of useful contact information, and any other relevant material or publications. These materials can be found at www.renalmd.org/ncap or <http://www.aspneph.com/> (insert actual link when available).
- The initiation letter and the imminent transfer letter are designed to work best if used by a pediatric nephrologist in that sequence.

Checklist for Drafting Initiation Letter

- This patient is in CKD stage 1 / 2 / 3 / 4 / 5 - no RRT / 5 – on RRT
- (If CKD 5 on RRT) This patient is currently a:
 - Renal transplant recipient – living donor (Date of transplant)
 - Renal transplant recipient – deceased donor (Date of transplant)
 - Hemodialysis patient at (insert name of facility, prescription, vascular access type, vascular access surgeon)
 - Peritoneal dialysis patient at (insert name of facility, prescription, PD catheter surgeon)
- This patient's CKD is due to [write in]:
 - Congenital disorders including:
 - Obstructive uropathy
 - Renal dysplasia/multicystic dysplasia/hypoplasia/aplasia
 - Prune Belly syndrome
 - Reflux nephropathy

- Focal sclerosing glomerulonephritis
 - Rapidly progressive glomerulonephritis
 - Lupus glomerulonephritis
 - ARPKD
 - ADPKD
 - Nephronophthisis-medullary cystic kidney disease complex
 - Cystinosis
 - “fill in the blank”
 - “blank” Syndrome consisting of “fill in the blanks”
- Active problems that need to be addressed include [write in]:
 - Hypertension
 - Urinary tract infections
 - Secondary hyperparathyroidism
 - Anemia
 - High risk behaviors (smoking, drinking, illegal drug use)
 - Acid-base disorders (e.g., metabolic acidosis, renal tubular acidosis)
 - Nephrotic syndrome
 - Nutrition
 - Psychosocial status
 - Other congenital anomalies or disabilities
- This patient is currently on the following medications (please manually input all medications) OR the medication list is attached
- The patient’s primary insurance is [write in]:
 - Medicare
 - Medicaid
 - SCHIP Program
 - Commercial
 - Military
- The patient’s secondary insurance is [write in]:
 - Medicare
 - Medicaid
 - SCHIP Program
 - Commercial
 - Military
- The primary contact person for insurance matters for this patient is:
 - Insert name
 - Insert Role [write in]
 - Social worker
 - Case manager
 - Practice manager
 - Other
 - Insert contact information

- The expected date of transfer of care will occur
 - Upon 18th birthday?
 - Upon 21st birthday?
 - Upon other birthday or date?
- The patient's family involvement in medical decision-making
- Other specialists involved in the patient's care [write in]
 - Urology
 - Cardiology
 - Neurology
 - GI
 - Psychology/Psychiatry
 - Surgery
 - Orthopedics
 - Therapists
 - "fill in the blank"

Checklist for Drafting Imminent Transfer Letter

- This patient is in CKD stage 1 / 2 / 3 / 4 / 5 - no RRT / 5 – on RRT
- (If CKD 5 on RRT) This patient is currently a:
 - Renal transplant recipient – living donor (Date of transplant)
 - Renal transplant recipient – deceased donor (Date of transplant)
 - Hemodialysis patient at (insert name of facility, prescription, vascular access type, vascular access surgeon)
 - Peritoneal dialysis patient at (insert name of facility, prescription, PD catheter surgeon)
- This patient's CKD is due to [write in]:
 - Congenital disorders including:
 - Obstructive uropathy
 - Renal dysplasia/multicystic dysplasia/hypoplasia/aplasia
 - Prune Belly syndrome
 - Reflux nephropathy
 - Focal sclerosing glomerulonephritis
 - Rapidly progressive glomerulonephritis
 - Lupus glomerulonephritis
 - ARPKD
 - ADPKD
 - Nephronophthisis-medullary cystic kidney disease complex
 - Cystinosis
 - "fill in the blank"
 - "blank" Syndrome consisting of "fill in the blanks"
- Active problems that need to be addressed include [write in]:
 - Hypertension
 - Urinary tract infections
 - Secondary hyperparathyroidism

- Anemia
- High risk behaviors (smoking, drinking, illegal drug use)
- Acid-base disorders (e.g., metabolic acidosis, renal tubular acidosis)
- Nephrotic syndrome
- Nutrition
- Psychosocial status
- Other congenital anomalies or disabilities
- This patient is currently on the following medications – please manually input all medications or the medication list is attached
- The patient’s primary insurance is [write in]:
 - Medicare
 - Medicaid
 - SCHIP Program
 - Commercial
 - Military
- The patient’s secondary insurance is [write in]:
 - Medicare
 - Medicaid
 - SCHIP Program
 - Commercial
 - Military
- The primary contact person for insurance matters for this patient is:
 - Insert name
 - Insert Role [write in]
 - Social worker
 - Case manager
 - Practice manager
 - Other
 - Insert contact information
- The family’s involvement in medical decision-making
- Other specialists involved in the patient’s care [write in]
 - Urology
 - Cardiology
 - Neurology
 - GI
 - Psychology/Psychiatry
 - Surgery
 - Orthopedics
 - Therapists
 - “fill in the blank”

Caring for Transient Dialysis Patients

It is common for dialysis patients to travel to another city for a short time to visit family, or for vacation. If the travel is longer than a couple of days, then the patient needs to be dialyzed in the city of travel. Often, the patient needs dialysis in the area they are visiting for only one or two treatments, but sometimes it may be longer. When patients travel and are dialyzed in a center away from their home dialysis facility as a transient patient, this situation is a transition of care that may have a significant impact on how patients feel or their overall health. It is important that the dialysis treatments at the transient facility be as safe as possible both for, the travelling patient and for the accepting dialysis unit. Continuity of care and communication are of the utmost importance during the few treatments received at the accepting unit.

The medical records that are sent over from the patient's home unit to the accepting unit is often bulky and may contain many copies of treatment sheets or other information, which is not always helpful in the care of the patient, and may take time away from the busy nephrologist or dialysis staff. The records sent often do not contain necessary information needed for optimal care of the patients when they are traveling. Below is a sample transfer form that the Forum Medical Advisory Council (MAC) helped to create which contains some of the information we feel is most important for the receiving dialysis facility to know to deliver the best care to the patient while dialyzing at the facility away from home. We also created this form to help you and your facility eliminate unnecessary paperwork and only included what we felt was the most useful information

There have been concerns expressed by dialysis patients that when they travel to another dialysis facility as a transient patient, they may not receive the medications they normally receive on dialysis at their home facility. One major reason this may occur is that many dialysis facilities do not carry the same medications on their formulary. To assist physicians in converting the dose of a medication a patient is currently receiving on dialysis to a substitute medication that is available or less costly, the IPRO ESRD Network of New England (Network 1) Medical Review Board, developed a Medication Conversion Tool. The Forum of ESRD Network's Medical Advisory Council finalized and approved the tool for national use by all dialysis facilities and providers. The tool is current available on the National Forum of ESRD Networks [website](#) under resources-> Toolkits-> MAC Toolkits. The link to the toolkit is below. Medications converted using this tool must be approved or ordered by the patient's Nephrologist, however we encourage all care providers and patients to share this guide with their care teams. This guide or tool allows the user to enter the current dose of medication (including ESAs, Vitamin D analogs, and IV iron formulations) and the tool will calculate the equivalent dose of the substitute medication. The tool also lists the substitute medication dose forms available and the maximum recommended dose. The medication should be ordered and approved by the Nephrologist.

We hope you will find using the sample transfer form and medication tool useful for in your care of your dialysis patients while traveling to another facility. We feel these tools may help make the transition of traveling dialysis patients from one dialysis facility to another more efficient and will help to minimize risk to your patients and help patients traveling feel safer in the dialysis facilities they are visiting.

Medication Conversion Guide: <http://esrdnetworks.org/resources/toolkits/mac-toolkits-1>

Sample Transient Dialysis Patient Form (v1.0)

<http://esrdnetworks.org/resources/toolkits/mac-toolkits-1/new-toolkit-transitions-of-care-toolkit>

Dialysis Facility Name and Location:

Dialysis Facility Contact Name:

Dialysis Facility Contact Phone: _____ Fax: _____

*****Please fill in all information

Patient Name: _____ Date of Birth: _____

Requested Dates: _____ Patient Phone: _____

Referring Facility: _____ Referring Facility Phone: _____

Referring Facility Contact Person Name: _____ Code Status: full code DNR Other:

How will Patient be transported to the center: _____

Is the Patient Ambulatory: Yes No

Is the Patient Trach or Vent Dependent: Yes No

Can Patient sit in standard chair to dialyze: Yes No

Can Patient Sign own legal consents: Yes No

Has pt had disruptive behavior on dialysis : Yes No

Hospitalizations in previous 3 months? Yes No

If yes, please provide dx: _____

Has patient had Infection(s) in last 60 days? Yes No

If yes, please provide dx: _____

If pt is on antibiotic, please list name, dose and schedule: _____

Number of missed treatments within past 2 weeks (before travel): _____

Current Dialysis Access: AVF AVG Cuffed-Tunneled Catheter Other: _____

If AVF, Buttoholes? Yes No Needle Size: 15g 16g 17g

Is patient > 2 kg above EDW at his last dialysis treatment? Yes No

Meds given on dialysis -Include dose, frequency, and date last given:

Anything else regarding patient we should be aware of: _____

Name of patient's Primary Nephrologist to contact for any questions: _____

Phone number/pager of Primary Nephrologist to contact if any questions: _____

**** Please fax copy of the following (required):**

- Current Dialysis Prescription Orders
- Updated Medication List and Allergies. **Please include medications given on dialysis**
- Current Month and previous month's Labs (including URR), electrolytes, Calcium, Phos, and Hgb
- Problem List/Comorbiditis or H+P within 1 year
- EKG within 1 year
- Hepatitis (Hep) B Surface Ag results within 1 month, Hep B S Antibody and Hep C Antibody within 1 year
- Demographic information
- Completed 2728 Form
- Copies of all active insurance cards (front and back)
- MSP Questionnaire
- Authorization to Treat & Financial Consent Forms
- Involvement of Care Form
- Confidentiality Form (demographic information and Privacy Practices)
- PPD results within 1 yr, if + PPD please send CXR results within 1 yr
- Patients transferring for ≥30 days, also need up-to-date comprehensive assessment(s) and plan of care

Local Address and Telephone Number, please: _____

****We may transfer transient patient to another of our facilities if chair needed for new patient start**

Form updated by ESRD Forum of Networks MAC, V1.0- David Henner, DO 4/5/2019

Sample Confidentiality Agreement

CONFIDENTIALITY AND USE AGREEMENT

Practice Name: _____

Date: _____

_____ grants the above named Practice the ability to permit its employees to access, through the _____ system, certain electronic medical records (including copies and portions thereof) maintained by _____ (hereinafter "Electronic Medical Records"), subject to Practice's compliance with the terms and conditions set forth below.

1. Practice acknowledges that Electronic Medical Records contain sensitive patient and clinical information, the confidentiality of which is protected by various laws, regulations and policies. Practice agrees that when any member of its staff accesses any Electronic Medical Record, that staff member will comply with all existing policies and procedures concerning the security and confidentiality of Electronic Medical Records. Practice further agrees that it will comply with the Health Insurance Portability and Accountability Act of 1996 and related regulations, as they may be amended from time to time, as well as any other applicable law, and that it will provide to _____ all necessary documentation related to its staff's compliance.
2. Practice shall not permit any member of its staff to access any Electronic Medical Record except to the extent necessary to provide services to patients with whom a physician within Practice has a treatment relationship, provided however that each staff member permitted access shall have first executed his or her own Confidentiality and Use Agreement.
3. Practice agrees to not permit the transmission of any Electronic Medical Record over the Internet (whether through electronic mail, file transfer protocol or other means of electronic transmission) except through use of the _____ system, by means of an electronic mail account provided and maintained by _____, or by any other method approved by _____.
4. Practice agrees that it will not permit the saving or copying of any Electronic Medical Record to any portable media storage device such as a USB drive, CD, DVD, or flash memory.
5. Practice agrees that access via the _____ system will be permitted only through the use of a desktop or laptop computer, or by a handheld or portable digital assistant device such as a BlackBerry, Treo or iPhone approved in advance for such access by _____. User agrees to comply with any security requirements that _____ may issue from time to time concerning computers or devices used for access. Such requirements are hereby incorporated by reference. User agrees that in the absence of any requirements issued by _____, it will ensure that the computer from which access is being made will have functioning, up-to-date antivirus and firewall software, and that any handheld or portable digital assistant device used for access will be locked

by a password when not in use. In no event shall Practice permit access to any Electronic Medical Record using a public computer, such as in an Internet cafe' or library.

6. Practice agrees to safeguard any Issued tokens, usernames and passwords, and agrees that it will not permit any of its staff to write down their username and password on the same piece of paper or otherwise place such username and password in an area where it may be intercepted by another person. Practice agrees that It will not release or permit the use by any unauthorized person, any issued token, username, or password. Practice agrees to notify the _____ Service Center immediately if it becomes aware or suspects that any person has unauthorized access to any issued token, username, or password or if any issued token becomes lost or stolen.
7. Practice agrees to not permit any use or access of any Electronic Medical Record, either on _____ premises or remotely, by any member of its staff not needing such access in connection with a particular treatment relationship. Practice further agrees to require that members of its staff fully log out of the _____ system immediately upon the staff member's completion of that session of use of the system.
8. Practice agrees to permit access to Electronic Medical Records only of those individuals with whom one or more of Practice's physicians has a treatment relationship. Practice also agrees to permit access only to the amount of the Electronic Medical Record necessary to perform the job functions related to that treatment relationship, by a particular authorized individual. Practice agrees that its staff members are strictly prohibited from accessing non-patient information. Any other access requires the express permission of _____.
9. Practice agrees that it shall not permit access to any Electronic Medical Record for "curiosity viewing" or "surfing" of patient records. Practice agrees that this includes viewing Electronic Medical Record of children, other family members, friends or coworkers, unless access is necessary to provide services to patients with whom Practice has a treatment relationship.
10. Practice agrees that its obligations under this Agreement will continue in the event that _____ terminates Practice's access to the Electronic Medical Records addressed under this Agreement.
11. In its sole discretion, with or without cause, _____ shall have the unconditional right to terminate Practice's access to any or all Electronic Medical Records immediately and without prior notice. As applicable, Practice understands that any breaches of this Agreement may be referred to the appropriate peer review process as a breach of confidentiality as defined in the Bylaws of the Professional Staff or the Disciplinary Action Policy, with or without notice at _____'s solo discretion.
12. _____ SHALL NOT BE RESPONSIBLE OR LIABLE FOR PRACTICE'S INABILITY TO ACCESS ANY INFORMATION ELECTRONICALLY, WHETHER BY REASON OF HUMAN ERROR, ACT OF NATURE,

TECHNICAL FAILURE OR INCOMPATIBILITY, OR ANY OTHER CAUSE. _____ SHALL NOT BE LIABLE FOR ANY DAMAGES ARISING AS A RESULT OF _____ TERMINATION OF THIS AGREEMENT.

13. PRACTICE AGREES TO DEFEND, INDEMNIFY AND HOLD _____ HARMLESS FROM AND AGAINST ANY CLAIMS BROUGHT AGAINST _____ ARISING FROM THIS AGREEMENT OR PRACTICE’S ACCESS TO THE _____ SYSTEM.

14. This Agreement together with any documents referred to or incorporated herein constitutes the entire agreement between the parties with respect to its subject matter, and supersedes all prior agreements, proposals, negotiations, representations or communications relating to the subject matter. _____ may amend the terms of this Agreement by providing notice of such amendments to Practice, and continued access by Practice or its employees thereafter shall constitute acceptance of such amendments. Both parties acknowledge that they have not been induced to enter into this Agreement by any representations or promises not specifically stated herein.

15. This Agreement shall be interpreted, construed, and enforced pursuant to and in accordance with the laws of the State of _____, not including its choice-of-law provisions. The federal or state courts in _____ County _____ shall constitute the sole and exclusive venue for any legal proceeding arising out of the Agreement, and Physician hereby consents to the personal jurisdiction of such courts in respect to any legal proceeding arising out of this Agreement.

HEALTHCARE SYSTEM

PRACTICE

Signature

Signature

Typed or Printed Name

Typed or Printed Name

Title

Title