

INTENSIVE INTERVENTION WITH THE

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**Guidance & Resources
for Dialysis Facility
Personnel**



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This guide is meant as a tool for use with the non-adherent patient. It is **NOT INTENDED** for use with the violent, aggressive, or hostile patient. Those patients require other interventions not covered in this guide. *Revisions were completed under the Centers for Medicare & Medicaid Services (Baltimore, MD) contract #HHSM-500-2010-NW014C.*

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The *Intensive Intervention with the Non-adherent Patient Guide* was developed by the ESRD Network of Texas, Inc. (Network 14), Medical Review Board, Executive Committee and Patient Advisory Committee as a guide for renal professionals.

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INTRODUCTION

"Non-adherence" is almost a way of life with some Americans (see [Appendix A](#) for facts related to non-adherence). Many people with diabetes, for instance, do not monitor their insulin as they know they should. A lot of people do not take antibiotics for the full duration (usually ten days), as they have been instructed. Most Americans do not exercise or eat right even though they know they should. Being diagnosed with End Stage Renal Disease seldom changes this pervasive behavior.

Most dialysis patients overload on fluids or "cheat" on their diet from time to time. While this can be a problem, in most cases the staff can see that the patients are making a sincere effort to follow the regimen. There are some patients, however, who flagrantly disregard the medical regimen and make it clear to the staff that they have no intention of following it. For these few patients, their non-adherence is not only risky, but it also makes it difficult for their doctors and renal staff to continue working with them.

While the temptation may be to dismiss these patients, it is important to remember non-adherence is not an acceptable reason for discharge as documented in the Conditions for Coverage (CfC). In addition, it is important to acknowledge that their refusal to follow the regimen may be, in and of itself, a symptom. They may have psychological or emotional problems that will not allow them to develop insight.

They may have unknown comprehensive stressors that prevent them from cooperating, such as:

- Fear of pain
- Lack of transportation
- Lack of childcare
- Demands from the job

Or they may have experienced a recent life change event that changed their desire to be healthy or their ability to cope. Finally, some of these patients may not have a good reason for refusing to attend all treatments; they just miss treatments.

Whatever the reason for non-adherence, as professionals and under the regulations, we must do everything possible to eliminate any deterrents to adherence and to enhance those factors that will encourage positive change. This will take some time and effort on everyone's part, but can be extremely rewarding when the staff see a change in the patient's behavior.

The following steps are suggested as a way to intervene with patients who repeatedly skip treatments without a reasonable explanation or who repeatedly sign off before their dialysis treatment is complete. These steps are not all-inclusive, and if there is something else a staff member can envision, it should certainly be tried. Also, the *order* of these steps is dynamic; if staff find that doing one step prior to another is more effective, then it should be done this way. Finally, the steps are not absolute; if one particular step does not apply, feel free to skip it.

THE GOAL OF THIS INTERVENTION EFFORT IS A CHANGE IN BEHAVIOR LEADING TO ADEQUATE DIALYSIS AND BETTER OUTCOMES AND THEREFORE AN IMPROVEMENT IN THE PATIENT'S HEALTH. THIS IS NOT INTENDED AS A DISMISSAL PROCESS.

The ESRD Network of Texas stands ready to consult with any staff member in working with non-adherent patients. Through our combined years of experience it may be that one of us has come up with a solution that your staff has not tried. Please call Network 14 at (972) 503-3215 and ask for the Patient Services Department, the Quality Improvement Coordinator, or the Executive Director, and we will be glad to help.

SUGGESTED STEPS IN AN INTENSIVE INTERVENTION WITH NON-ADHERENT DIALYSIS PATIENTS

1. Treatment Team Consensus: The treatment team should discuss the patient's behavior during either comprehensive assessment review or a QAPI meeting and reach an agreement that the behavior is a problem and that an Intensive Intervention is needed.
2. Complete a focused comprehensive history, with the focus being an assessment of some possible causes of the present problem.
 - a. Assess for peripheral contributing problems, such as:
 - i. Loss of income
 - ii. Transportation problems
 - iii. Marital discord
 - iv. Illness in the family
 - v. Conflicting family obligations (i.e., babysitting/care giving)
 - b. If any comprehensive problems are found, address immediately.
 - c. Evaluate for improvement (using the evaluation procedure that follows on page 8); if there is no improvement, proceed to another step.
3. Rule out significant life change events (LCE).
 - a. An LCE is an event that will result in changes in coping or adapting skills for several weeks to several months. Some LCEs are:
 - i. Death in the family
 - ii. Divorce
 - iii. Problems with the police or going to court
 - iv. Change in housing
 - v. Hospitalization/new illness
 - vi. Loss of primary caregiver

For a more extensive list of LCEs please see [Appendix B](#).

- b. If any LCEs are identified, help the patient either through a referral for assistance outside the clinic or through staff assistance.
 - c. Evaluate for improvement (monthly, at minimum); if there is none, proceed to another step.
4. Eliminate (whenever possible) the discomforts of dialysis.
- a. Patients often "hate" to come to dialysis and so miss treatments or cut treatments short because they are so uncomfortable during the treatment; check for:
 - i. Leg cramps
 - ii. Restless Legs Syndrome
 - iii. Pain
 - iv. Being too cold
 - v. Patient/staff friction
 - vi. Need to eat (especially for diabetic patients)
 - vii. Need to smoke
 - viii. Restroom use
 - ix. Needle phobia
 - b. Address each of these "discomforts" on a case-by-case basis.
 - c. Evaluate for improvement; if there is none, proceed to another step.
5. Convene a meeting with the patient and the treatment team to discuss the harm of skipping/shortening treatments. Invite the family if the patient agrees. Wait two or three weeks. If there is still no improvement, proceed to another step.
6. Have the social worker or another staff member develop a "therapeutic alliance" with the patient, where the two work together to achieve adherence to the regimen.
- a. Meet with patient *weekly* or every time s/he comes.
 - i. Repeat time and again the benefits of adherence to the entire regimen (medications, fluid/diet, and dialysis time) in simple terms. (A review of Patient Education Techniques follows on page 10.)
 - ii. Attempt various techniques in patient education.
 - iii. Be certain patient understands consequences of non-adherence.
 - iv. Give the patient the Heart Balloon Brochure.
 - b. Discuss health literacy and teach back methods, such as, the *Ask Me Three Method*.

Example

- i. What is my main problem?
- ii. What do I need to do?
- iii. Why is it important for me to do this?

- c. Evaluate for improvement (monthly, at minimum); if there is none, proceed to another step.
7. Mobilize the patient mentor program or utilize your Facility Patient Representative (FPR) in your clinic and have a fellow patient meet with the patient to discuss adherence to the regimen.
 - a. Before setting up the meeting, ask the mentor or FPR if s/he is willing to do this and ask the non-adherent patient if s/he is willing to talk to the mentor. If either refuses, do not do this.
 - b. If both agree, facilitate the meeting and offer support and resources to the mentor or FPR, as usual.
8. With the patient's permission, include the patient's family.
 - a. If the patient has no immediate family, include any significant other that is listed in the current comprehensive assessment.
 - b. The family can be made aware of the seriousness of the patient's inadequate dialysis treatments.
 - c. If the patient does not approve of the family or friends being involved, proceed to another step.
9. Ask the patient if they would like to participate in a Patient Care Conference with the ESRD Network and their Treatment Team to work together to address everyone's concerns and develop a plan to move forward.
10. Enter into a *BEHAVIOR* Agreement with the patient.
 - a. For assistance on writing an agreement, call the Network 14 Patient Services Department.
 - b. Assign a staff member to help the patient achieve the goal. Any staff member can serve in this role. Ideally, it would be the doctor, nurse, or social worker, but it can be the dietitian, CCHT/PCT, or any other staff member.
 - c. Monitor over 30, 60, or 90 days.
 - d. Evaluate for improvement; if there is none, proceed to another step.
11. Have the nurse or social worker write the patient an informal letter voicing concern that this behavior is self-destructive and could have long-term effects (see [Appendix C](#) for an example letter). This will need to be done verbally with patients who cannot read; patients with limited English-reading skills should receive the letter in their own language if possible or have it translated into their own language.
 - a. With the patient's written permission, send a copy of the letter to the patient's family.

- b. If the patient will not give permission, do not inform the family about this letter.
 - c. Wait two or three weeks. If there is no improvement, proceed to another step.
12. Review the problem with the entire treatment team in QAPI or a comprehensive assessment meeting and write a formal letter of warning from the medical director or attending physician (see [Appendix C](#) for an example letter); at this time write a warning in bold, capital letters:

“Continuation Of This Behavior Could Result In Your Being Placed On Another Shift, And/Or We May Wait Until You Are Actually In The Clinic Before We Set Up Your Machine. This Could Mean As Much As A Half Hour Wait On Your Part And Possibly A Shortened Treatment Since You Will Be Taken Off Dialysis When The Shift Is Over.”

For patients who cannot read, this warning will need to be given verbally. Patients with limited English-reading skills will need to have the letter written in their native language or have it translated for them.

NOTE: Be sure to take extenuating circumstances (such as transportation) into account. Ask the patient in this letter to meet with the doctor or any member of the treatment team to discuss the problem. Wait another two or three weeks.

- a. With the patient’s permission, include the patient’s family in this discussion.
 - b. If the patient’s family cannot be included in the discussion, with the patient’s permission, inform them of the contents of the letter.
13. Discuss the problem a *third time* in QAPI or a comprehensive assessment meeting and determine if the problematic behavior is totally unacceptable to the staff or disrupts the orderly functioning of the clinic.
- a. If the answer to the above is "no," do the following:
 - i. Inform the patient of the team's decision to change the patient’s shift and that s/he will have to wait to have his/her machine set up before each and every treatment. (Do not set up the dialysis machine for the patient until s/he walks in the door; the patient will have to wait.)
 - ii. If the patient shows up late for a treatment and your clinic closes or another shift is scheduled before his/her treatment is complete, stop his/her dialysis at the end of the shift. It was the patient’s choice to shorten the treatment.
 - iii. Continue the therapeutic alliance efforts, as described above, and document the efforts.
 - b. If the answer to the above is "yes," change the patient's dialysis shift as instructed above, contact Network 14, and ask for assistance in continued intervention efforts.

EVALUATION OF PROGRESS

Evaluating the progress of the **Intensive Intervention** involves both qualitative and quantitative measurements. Both need to be considered equally. The qualitative measurement involves the observation by the staff, especially the patient's "ally," if there is one, as to the effort the patient is making. One patient may be cooperative, make an effort, and show a desire to change, but has a hard time achieving the goals. Another may be cavalier about the plan, ignore efforts to help, and disregard the suggestions of the staff. Still a third may defy the plan entirely and even blame the staff for not doing their jobs as the reason s/he does not come to dialysis. A crucial factor is to evaluate whether the patient is cooperating or not with the staff. Some patients actually *could* change if they wanted, while others just do not want to make the effort. Certainly the patient who shows an attitude of cooperation and willingness to work with the staff should be given every opportunity to do so. On the other hand, the patient who is able but unwilling to change should be moved quickly through the steps of the plan.

The quantitative measurement involves tallying the number of hours of dialysis the patient receives in the present month and comparing this total to the number of hours in the previous month. If the patient has made some gain, remember that even one hour more than the previous month represents progress!

If the patient has made a small progress (one to four hours more than last month), continue on the same step with the same plan. Give the patient lots of praise and positive reinforcement. Brag to fellow staff members about how well the patient is doing. Have the doctor mention it on rounds. Mention to the patient that any change in behavior that is going to last a long time is going to be slow. Continue with the same intervention and encourage the patient to continue with the small but meaningful progress. Consider making a graph showing the patient how much scheduled time has been given.

If the progress is substantial (four hours more than the previous month, but still short of the prescribed time), stay on the same step but try another intervention. Review the types of patient education techniques and try a technique other than the one you have been using. The present technique has most likely reaped all the benefits it is going to because it led to substantial progress. Another technique should be attempted within the same step.

If the patient has become compliant, continue on the same intervention technique, but meet less often with the patient and at different times. Do not meet weekly, as before, but meet at various intervals. Further, if you always met with the patient on a Wednesday, try a Monday or a Friday instead. Change the approach you are taking, but keep the intervention technique the same for at least another month. If the patient continues doing this well after a second month, you can discontinue the Intensive Intervention. The Readiness of Change Ruler can be assessed and utilized in evaluating progress, which can be found in the *Motivational Interviewing Strategies and Techniques* web resource tool (see [Appendix D](#) for a brief list of the stages).

When both the qualitative and the quantitative measurements are made with the patient, the patient who is trying but not succeeding can still feel that s/he has gained some ground. This gain is in the area of *social reinforcement*, with the staff recognizing that the patient made a good effort.

LIFE CHANGE EVENTS

The list of Life Change Events (LCEs) in [Appendix B](#) has been taken from the Holmes and Rahe Social Readjustment Rating Scale (1967). It includes typical LCEs that most people in our society may experience at one time or another in their lives. Most dialysis patients experience some LCEs when they first start dialysis. The initial comprehensive assessment addresses these and helps the patient adjust to life on dialysis. Thus, *this list is intended for those patients who are past their initial adjustment*. The patient who is non-adherent from the start requires intensive patient education and help with adjusting to dialysis, not an assessment for Life Change Events.

Although the LCEs are common, they can still affect our lives in various ways. LCEs may result in an inability to handle daily problems with our usual coping skills. Routines frequently become disrupted and things that were previously important may take a backseat. For example, doing routine chores like making arrangements for a ride become almost insurmountable. This is due to the extreme stress of some of these events. The stress of any one of these events may continue from a few days to a few weeks. Because our usual coping skills do not work for a short time, other daily stressors, which would not usually disrupt our daily lives, may now do so. It is anticipated that within a few days to a few weeks the stress of the LCE will wear off or the patient will achieve a new level of functioning that will allow him/her to cope once again with daily problems. It usually takes about six weeks for scar tissue to form, both in our bodies and in our emotions! If the stress and inability to cope with the LCE continues longer than a few weeks, a referral for psychological help is advised.

The Holmes and Rahe Social Readjustment Rating Scale can be administered and scored by a professional to determine the level of stress a patient may experience. Most dialysis patients experience some of these events, such as “business readjustment” or “change in financial state,” at the onset of dialysis. **The list does not include a scoring sheet, as it is not intended as a psychological test, but merely a review of some of the events that could affect the daily coping skills of our patients and could result in non-adherence.** The LCEs are listed in order of severity. Most dialysis patients experience some of these events at the onset of dialysis.

APPROACHES TO PATIENT EDUCATION

Before trying to teach a patient about the dialysis regimen, it is important to assess the patient's level of learning. Different people learn in different ways! Some learn simply by being told, others by watching television, and still others by listening to the radio. Very few learn by reading, as very few people are readers. Some patients would rather a staff member sit and explain something and then have an opportunity to ask questions, while others want staff to hand them a pamphlet, give them time to read it, then return later for a question and answer session.

Many language barriers exist that present a special challenge in educating patients who speak little or no English. Remember that family is not a preferred choice for the provision of medical translation services. The CfC (2008) states in V101, "the facility and its staff must operate and furnish services in compliance with applicable federal, State, and local laws and regulations pertaining to licensure and any other relevant health and safety requirements." Information regarding interpretive guidance can be found through the Department of Justice Civil Rights Division for Title III related to public accommodations under the Americans with Disabilities Act (ADA). (Pamphlets and resources in languages other than English can be obtained by contacting one of the kidney organizations included in [Appendix F](#).)

Even though they may speak English fluently, a large number of Americans have a low health literacy level. One out of five American adults reads at the 5th grade level or below, and the average American reads at the 8th to 9th grade level. Yet most health care materials are written above the 10th grade reading level. Socio-economic status is linked to literacy with one-half to one-third of welfare recipients performing at the lowest literacy levels. Age is also linked to literacy with more than 66% of adults, age 60 and over, having either inadequate or marginal literacy skills. Patients with low health literacy and chronic disease, such as kidney failure, have less knowledge of their disease and its treatment and fewer correct self-management skills than literate patients. Research suggests that people with low literacy are less able to comply with treatments. People who are non-readers or poor readers generally try to hide it. The burden is upon the health care professional to assess each patient's status and respond with education that the patient can *understand*. This is especially true when dealing with a patient in an Intensive Intervention. Assessing learning levels can be done by asking a few questions and by making a few observations.

What is the patient's level of education or functional competency level? What is (or was) the patient's profession or skill? Is this a profession that requires a lot of learning of new skills and problem solving? Does the patient read during dialysis or watch television? Does the patient ask more advanced questions ("What is my URR this month?") or simpler questions ("How long do I have to keep doing this dialysis stuff?")? When explaining something to the patient, does it have to be repeated several times before the patient grasps the concept? Most importantly, does the patient even ask questions or does s/he simply accept whatever the staff says? Does the patient always direct you to give instructions to a spouse, child or friend? These and many other observations can give one an idea of the patient's learning level and how s/he problem solves, which may indicate the best medium for teaching.

Strategies to Improve Education Materials

Recognize and address limited health literacy and understanding

Did you know?

- Most patients forget up to 80% of what their doctors tell them as soon as they leave.
- Nearly 50% of what they do remember is *recalled incorrectly*.
- A 2006 study examined patients' abilities to understand five common instructions on prescription medications: both patients with adequate and low literacy had difficulty understanding at least one of the five instructions.
- A disproportionate number of minorities and immigrants are estimated to have literacy problems:
 - 50% of Hispanics
 - 40% of Blacks
 - 33% of Asians
- About 48% of U.S. adults cannot read well enough to use a bus schedule.
- Nearly two of three foreign born individuals cannot read the instructions on a prescription bottle.
- More than 66% of U.S. adults, age 60 and over, have either inadequate or marginal literacy skills. Patients with low health literacy are:
 - less likely to be referred for kidney transplant
 - have worse control of chronic diseases
 - have higher mortality

Warning signs of limited health literacy and understanding

- Non-adherence with medications
- Asks fewer questions
- Does not follow through on tests or referrals
- States "I will read this when I get home," "I'll have (spouse, daughter, son) look at this when I get home," or "I forgot my glasses."
- Does not seem to pay attention
- Looks confused
- Blank stares

Use plain language

Plain language is communication that someone can understand the **first time** s/he reads or hears it. The concept of using plain language is closely related to the concept of health literacy and is critical to patient education. The benefit of using plain language is like a two-way street. It helps people understand information more rapidly and makes it easier for the person giving the information. To use plain language:

- Choose common, everyday words
- Patient-friendly words (replaces medical jargon and other difficult terms)
 - Salt instead of sodium
 - High blood pressure instead of hypertension
 - Swollen instead of edema
- Use examples and/or analogies whenever possible

- Arthritis: it's like a creaky hinge on a door
- Enlarged heart: it's like an overblown balloon
- Fluid overload: it's like drowning in fluid

A plain language thesaurus is online at www.plainlanguage.gov. See [Appendix E](#) for a list of common words used in medicine and suggested plain language alternatives.

Present information in an understandable format

- Be concise. Sentences should be no more than 15 words long, on average.
- Paragraphs should contain only one main idea.
- Get rid of unnecessary information. Focus only on what the patient needs to know.
- Use:
 - Simple words (1-2 syllables)
 - Short sentences (4-6 words)
 - Short paragraphs (2-3 sentences)
 - Headings and bullets
 - Lots of white space
 - No medical jargon
- Put the most important information first.

Convey information and confirm understanding

- Use “teach back” questioning following patient education to discover and assess if patient understood.
- Do **not** ask:
 - “Do you understand?”
 - “Do you have any questions?”
- Ask patients to say back *in their own words* what you just taught or explained. Ask in a non-shaming way, such as:
 - “To be sure I/we did a good job of explaining this, please tell me what you heard.”
 - “I want to make sure I did a good job explaining your blood pressure medicines, because this can be confusing. Can you tell me what changes we decided to make and how you will take the medicine now?”
- What percent of the content can they recall and restate?

Train patients to use the *Ask Me Three* when they receive healthcare information. This method uses three simple, but essential, questions and answers for every healthcare interaction:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Examples of using this method for providing information to patients are:

Normal way: “We are concerned that you are not being adherent with your phosphate binders. This is important because your phosphorus and calcium will not be in balance if you aren't adherent, and this may cause bone disease.”

Ask Me Three embedded in instructions:

- *What is the main problem?*
 - We are worried that you are not taking your binder medication enough (*showing a picture or actual pill*).
 - This is a big problem because it can hurt your bones and heart.
- *What do you need to do about it?*
 - You need to follow your diet and take XX pills every time you eat.
- *Why is it important for you to do this?*
 - Your bones will weaken and may break
 - You will get heart problems
 - You may have to have amputations
 - You won't live as long

Normal way: “We are concerned that you are not being adherent with your Hemodialysis treatments. This is important because your body accumulates too much fluid and toxins if you aren't adherent and this may cause you to have heart failure or a stroke.”

Ask Me Three embedded in instructions:

- *What is the main problem?*
 - We are worried that you are missing too many treatments.
 - This is a big problem because it can hurt your heart or cause a stroke.
- *What do you need to do about it?*
 - You need to come to every treatment.
 - If you can't get here, you need to call us.
- *Why is it important for you to do this?*
 - You could die.
 - You could get kicked out of the clinic and have nowhere to get your dialysis.

Adherence requires understanding the information given and the risks and benefits, especially the WIIFM factor—*what's in it for me?*

It is safe to say that new techniques will be needed if the usual patient education used in the facility has failed to achieve the desired results. Don't assume that a non-adherent patient is just choosing to ignore what has been said. Consider first that the patient truly does not understand.

Please see [Appendix F](#) and the References for resource books on educating patients.

INTENSIVE INTERVENTION TECHNIQUES

There are several intervention techniques that can be used when assisting patients to reach their optimal potential. It is important to know your patients and use techniques that complement their personality and educational needs. The following are some suggestions for use in the change process.

1. **Personalizing the Treatment Plan**

Treatment Plans that include only medical objectives are often very impersonal to patients. A Treatment Plan can be used to set personal and medical goals. A patient who has always wanted to see Alaska can include this in the treatment plan. Every time the patient is compliant s/he can reward him/herself by setting aside a dollar for the “See Alaska Fund.” Including familial goals in the Treatment Plan could be helpful. “Take a walk with my wife once a week” is certainly an appropriate personal goal that can find a meaningful place in the Treatment Plan and achieve a medical goal, as well. Remember to ask how dialysis is affecting other parts of the patients’ lives.

2. **Teaching by Telling Stories**

Many patients will listen to a story before they will listen to a lecture. Telling patients a story about another patient who had a hard time with compliance but managed to overcome it could be very helpful. It is best to use stories that are true without using a patient’s name or stories that are composites of several patients.

3. **Teaching through Appropriate Self-disclosure**

Self-disclosure can be a very effective teaching tool, but must be used carefully. The staff member must take care not to “unload” on a patient. Sharing a personal experience with a patient on problems with compliance could be a meaningful learning experience. Staff members who used to smoke or who have lost a lot of weight can share how they overcame those problems.

4. **Recounting a Famous Person Who Overcame Obstacles**

History is full of examples of people who had handicaps and achieved a lot or persons who overcame great obstacles to achieve their goals. Some patients have personal heroes and may be encouraged to learn that they overcame problems, as well.

5. **Behavior Modification Techniques**

Behavior modification can be an excellent means of changing non-adherent behavior. If there is a staff member who is familiar with contingency management, positive and negative reinforcement, or token and social reinforcement, then behavior modification can be used effectively. Learning the techniques, however, takes years of training, and using it incorrectly could be a waste of time. A referral to a trained clinician should be considered.

6. **Cognitive Restructuring**

Cognitive restructuring involves helping a patient change his/her mind about a situation. This involves changing faulty thinking, stopping thoughts before they escalate, replacing thought associations, and other such techniques. Like behavior modification, cognitive

restructuring is an excellent tool in the hands of a skilled clinician. Though, if there is no one on staff already trained in this area, learning while doing is not a good idea. A referral to a trained clinician should be considered.

7. **Spiritual Interventions**

Referring to great figures in the Bible or other spiritual leaders can be a very effective way of helping patients become compliant. A good example is a man by the name of Hezekiah in the Bible who was about to die but was granted a few extra years of life. Dialysis can be seen as being granted a few extra years of life rather than as a burden of dietary restrictions and disrupted schedules. Assistance may be offered in accessing a spiritual support system. Encouragement can be given to the patient to interact with church groups or friends.

8. **Reasons to Live**

The dialysis patient could be reminded that dialysis can be seen as a gift that allows us a little more time to live. Doing something with our lives is a worthy goal for all of us, but for the dialysis patient it is especially meaningful. Patients can be told, “You have been kept alive to do *something*. Perhaps it involves your family...” The book Reasons to Live by Amy Hempel (1995) is a delightful collection of stories about people who faced death and chose to live instead.

9. **Mobilizing Your Social Support System**

A very effective way of influencing people to discontinue undesirable behavior is to get their family and friends to help them. Patients can be taught ways that family and friends can be a resource to them in changing their behavior.

10. **Motivational Interviewing**

Motivational interviewing is a communication technique that can be an effective approach to improve and maintain treatment adherence in diverse populations. Motivational interviewing is a client-centered, semi-directive method of tapping into the person’s motivation to change behavior by developing discrepancy between current and ideal performance and exploring and resolving ambivalence within the individual. The goals of motivational interviewing are to establish rapport with the patient, elicit behavior change talk and establish commitment language from the patient. These goals can be accomplished by using the following methods:

1. Asking Permission—by doing this you are communicating respect for the patients.
2. Eliciting/Evoking Change Talk—allows the patient to give need or reason for the change that is become tested.
3. Exploring Importance and Confidence—in conjunction with the Readiness Change Ruler, allows you, the “change agent,” to understand how the patient views the importance of change and allows the patient to give voice to what they would need to do to change.
4. Open-Ended Questions—there is opportunity for richer, deeper dialogues that flow and build empathy with patients.

5. Reflective Listening—how you respond to the patient and reflect what you have heard can enrich the communication process and validate what the patient is saying.
6. Normalizing—offers the opportunity for you to show support and allow the patient permission to understand they are not alone in his/her struggle.
7. Decisional Balancing—can be used during any part of the change process and allows the patient to evaluate his/her behavior by looking at the good and not so good.
8. “The Columbo” approach—allows the “change agent” to address discrepancies without being judgmental or passing blame.
9. Affirmations—allow acknowledgment of the patient’s strengths.
10. Advice/Feedback—allows for the use of best practices or professional experience to be a guiding support to the patient.
11. Summaries—allow for reflection and progression to the next step in the process.
12. Therapeutic Paradox (also known as Paradoxical statements)—used in cases where little progress is made. Example: “Mr. J, I know that you have been coming to treatment three times a week; however, you continue to be 3 kilos over your dry weight. Maybe this is not the right time for you to make changes.” The expectation is that the patient will respond, “No, I know I need to change. It’s just hard putting it into practice.”

11. **Solution-Focused Brief Therapy**

Solution-focused brief therapy is an approach to psychotherapy based on solution-building rather than problem-solving. It explores the patients’ current resources and hopes for the future rather than problems and past causes. This therapy technique poses the miracle question: if tonight while you were asleep, a miracle happened and it resolved all your problems, what would you notice different tomorrow? The miracle question helps patients identify obstacles and stressors that are affecting their abilities to adhere to dialysis and follow their treatment plans. This technique can also identify things that patients might not have even realized were affecting their health and treatments. Once stressors are identified, the patient can begin to determine ways to relieve the stressors and improve treatment adherence.

12. **Shall We Talk Funerals?**

This technique is listed last for a reason. This is a “last-ditch effort” that has been found helpful in extreme cases. This technique consists of telling the patient something along the lines of, “Okay, I see that you are not going to do this compliance thing. It is your right to die with dignity. We will do what we can to make you comfortable. The doctor will prescribe pain medicine for you if you need it. It is better if you try to make funeral arrangements now so you will not leave a financial burden on your family. Shall we try to make some plans now?” This can be seen as cruel by some patients (and even staff) so it must be used only as a final resort, and then only very carefully!

TECHNIQUES OF SYMPTOM-TARGETED INTERVENTION

1. **Sessions are brief and manageable:** Developed by nephrology social worker Melissa McCool (2011), symptom-targeted intervention (STI) brings forward new methods to treat symptoms of depression in dialysis patients, using cognitive, behavioral, and mindfulness techniques.
2. **Identifying depression in dialysis patients:** STI seeks to identify and manage one symptom at a time. This approach allows the social worker and patient to focus their interactions.
3. **The social worker can establish rapport with the patient:** Since the focus is very specific, interactions with the patient are brief and can be done chair-side at the dialysis clinic.
4. **There is no stigma; the social worker sees every patient:** The relationship between the patient and nephrology social worker is without the stigma often associated with mental health treatment.
5. **There are no financial or transportation barriers:** There will be no transportation or financial barriers for the patient who comes to dialysis on a regular schedule and has access to a social worker. This allows the social worker to provide brief treatment interventions more frequently in order to monitor outcomes and alter subsequent intervention accordingly until the patient's symptoms improve.
6. **There is not a focus on clinical diagnosis:** There is no focus on clinical diagnosis of the depressed patient when using STI. Interventions address the symptom that is most problematic for the patient; it is irrelevant whether the symptom is caused by an adjustment disorder, dysthymia, a recurrent depressive episode, or another mood disorder. For this reason, STI is appropriate for almost all patients suffering from symptoms of depression.

NOTE: More information on Symptom-Targeted Intervention can be found on the Network 14 website.

In Summary

Dialysis patients are faced with life altering events from the time of diagnosis of ESRD. For many dialysis patients this information combined with other pre-existing stressors enhance what may appear to be a dismal outcome. It is important to remember the role we as professionals play in the healing process and to encourage patients to assume the opportunity to be change agents in their lives. Together everyone can make a difference!

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Appendix A

Facts Related to Non-adherence

FACT: Almost 11% of all hospital admissions are directly attributable to medication non-adherence

FACT: Poor compliance with medication regimens costs society \$290 billion per year

FACT: Approximately 23% of people entering nursing homes do so because they are unable to self medicate in their own homes

FACT: About one-third to half of patients in the U.S. do not take their medications as instructed, contributing to prolonged or additional illnesses

FACT: At the present time, more than 34 million households have an unpaid "caregiver" who is providing daily assistance to a family member age 18 or older

FACT: Medicare spending per patient year, 2010:

ESRD	\$75,043
Hemodialysis	\$87,561
Peritoneal Dialysis	\$66,751
Transplant	\$32,914

Appendix B

Holmes–Rahe Life Change Events

Death of spouse	Son or daughter leaving home
Divorce	Trouble with in-laws
Marital separation	Outstanding personal achievement
Jail term	Wife begins or stops work
Death of close family member	Begin or end school
Personal injury or illness	Change in living conditions
Marriage	Revision in personal habits
Fired at work	Trouble with boss
Marital reconciliation	Change in work hours or conditions
Retirement	Change in residence
Change in health of a family member	Change in schools
Pregnancy	Change in recreation
Sex difficulties	Change in church activities
Gain of new family member	Change in social activities
Business readjustment	Mortgage or loan less than \$30,000
Change in financial state	Change in sleeping habits
Death of close friend	Change in number of family get-togethers
Change to different line of work	Change in eating habits
Change in number of arguments with spouse	Vacation
Mortgage over \$100,000	Christmas alone
Foreclosure of mortgage or loan	Minor violations of the law
Change in responsibilities at work	

Appendix C

Sample Letters of Concern

Note: these letters are intended as samples and do not have to be copied word for word. It is best for clinic staff to write their own personalized letters that represent a similar tone and mood, but that contain similar information. Be careful to keep the reading level low.

First Letter of Concern

Date

Name and address of patient

Dear _____,

We the staff at _____ Dialysis Clinic want all our patients to be as healthy and strong as possible. This is why we work hard and plan carefully for each patient. The plan that we wrote with your help or input was intended to help you to have as long and healthy a life as possible. For this reason we have a treatment plan that we believe will do this.

We have a problem though. You are not _____. In order for the plan to work you need to _____. If there is anything that is keeping you from _____, we want to know about it. We will work with you to solve any problem that may keep you from reaching your goal of a long and healthy life.

Please stop by and visit with the social worker, _____, if there are any problems we can help you with. You can see the nurse, _____, if there is something about dialysis you don't like or don't understand.

Even if you can't think of anything that could be a problem, stop and see either of us anyway because we would like to talk about your plan of care for a long and healthy life.

See you soon!

Sincerely,

Social Worker

Nurse

Appendix C

Second Letter of Concern

Note: Before sending this letter, be sure to take extenuating circumstances, such as riding the city bus to get to and from dialysis, into account.

Date

Patient's name

Patient's address

Dear _____,

Recently we wrote you a letter and asked you to talk to our nurse or social worker about the problem of _____. The problem still continues.

We want to do everything possible to help you have a long and healthy life, but to achieve this you would need to _____.

If you continue to _____, we may have to take strong measures to help you help yourself. We do not want to do this, but will be forced to because of the problems your actions create for our clinic. WE WILL HAVE TO CHANGE YOUR TIME OF DIALYSIS TO ANOTHER TIME—ANOTHER DAY AND ANOTHER HOUR—THAT WILL CREATE FEWER PROBLEMS IN THE CLINIC. This could be harder on you so please come in and help us work out another solution.

Also, along with changing your shift time, WE ARE GOING TO WAIT UNTIL YOU ACTUALLY SHOW UP AT THE CLINIC BEFORE WE SET UP YOUR MACHINE. THIS MEANS YOU MAY HAVE TO WAIT AS LONG AS HALF AN HOUR AFTER YOU GET HERE BEFORE YOU START DIALYSIS. IF YOUR TREATMENT RUNS LONGER THAN THE TIME OUR CLINIC CLOSES, OR WHEN ANOTHER SHIFT IS SCHEDULED, YOUR TREATMENT WILL BE CUT SHORT.

We really do not want to do any of this and would rather have you _____ all the time. Please come in and talk to me so we can work this all out.

Sincerely,

Doctor

Appendix D

Stages of Readiness

1. **Pre-contemplative:** not aware or not considering a change
2. **Contemplative:** thinking about a change, but not taking action
3. **Action:** has made behavior change and is practicing it
4. **Maintenance:** retaining the behavior via reinforcement or learning
5. **Termination:** the end of the intervention; the behavior is a part of life and is no longer seen as a change that needs attention or reinforcement

Appendix E

Words to Watch

<i>Medical Word Examples:</i> Words frequently used by doctors and in health care instructions that are hard to understand for some patients.	
Problem Word	Consider Using
Ailment	Sickness, illness, problem with your health
Condition	How you feel; health problem
Dysfunction	Problem
Inhibitor	Drug that stops something that is bad for you
Intermittent	Off and on
Lesion	Wound; sore; infected patch of skin
Oral	By mouth
Procedure	Something done to treat your problem; operation
Vertigo	Dizziness
<i>Concept Word Examples:</i> Words used to describe an idea, metaphor, or notion.	
Problem Word	Consider Using
Active role	Taking part in
Avoid	Stay away from; do not use (or eat)
Collaborate	Work together
Factor	Other thing
Gauge	Measure; get a better idea of; test (dependent on context)
Landmark	Very important (adj.) Important event; turning point (n.)
Option	Choice
Referral	Ask you to see another doctor; get a second opinion
Wellness	Good health; feeling good
<i>Category Word Examples:</i> Words that describe a group or sub-set, and may be unfamiliar	
Problem Word	Consider Using
Activity	Something you do; something you do often, like driving a car
Adverse (reaction)	Bad
Cognitive	Learning; thinking
Hazardous	Not safe; dangerous
Generic	Product sold without a brand name, like ibuprofen (Advil is brand name)
Support	Help with your needs – for friendship, support, care
<i>Value Judgment Word Examples:</i> Words that may need an example or visual to convey their meaning with clarity.	
Problem Word	Consider Using
Adequate	Enough
Adjust	Fine-tune; change
Cautiously	With care; slowly
Excessive	Too much
Increase gradually	Add to
Moderately	Not too much
Progressive	Gets worse (or better)
Routinely	Often
Significantly	Enough to make a difference
Temporary	For a limited time; for about (an hour, day...)

Appendix F

Additional ResourcesBooks and articles

- Counts, C. S. (2008). *Core curriculum for nephrology nursing* (4th ed.). Pitman, NJ: American Nephrology Nurses' Association.
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Magazines and web resources

For Patients Only by Dialysis Incorporated Publishing

Life Options by the Kidney School

“Patient Plan – Phases I through 4” by the American Association of Kidney Patients (AAKP)

Renalife by the American Association of Kidney Patients (AAKP)

Appendix F

The ESRD Network of Texas, Inc. has provided to each unit, and available for purchase at a nominal price, two patient education videos on Dialysis Adequacy and Vascular Access.

This booklet, along with some of the material referenced and/or included in the additional resources section, can be accessed on the ESRD Network of Texas, Inc. website, www.esrdnetwork.org.

If you need assistance searching for or obtaining this material from the Network 14 website, please contact the Network 14 office at 972-503-3215 or info@nw14.esrd.net.