OPEN CONNECTION

Starting the home hemodialysis conversation before, during, and after training
Open Connection

Starting the home hemodialysis conversation

Open Connection, Starting the home hemodialysis conversation was written to help you develop a relationship with your NxStage home hemodialysis patients during orientation, training and the first 90 days at home. We hope that by frequently talking to your patients and engaging them with self-management skills this will strengthen your connection and boost the confidence of patients at home.

Any member of the Home Team can use the information in this booklet as a guide to establish an open line of communication and to set expectations; setting expectations upfront can make a positive difference in a patient’s time on home dialysis.

Open Connection was crafted using open-ended questions. An open-ended question is designed to encourage a full answer using the subject’s own knowledge and/or feelings. It is the opposite of a closed-ended question, which encourages a short or single-word answer, usually “yes” or “no.” Open-ended questions tend to be more objective and less leading than questions that are closed-ended.

Typically, open-ended questions begin with words like “why” and “how” or phrases such as “tell me about” or “describe.” Sometimes open-ended questions may not technically be questions, but statements that implicitly ask for a response.

The ability to ask open-ended questions is important in many vocations, including education, counseling, mediation, investigative work, and in nursing.

Closed-ended Question
Are you happy with your health insurance plan?

Open-ended Question
Tell me about your relationship with your Home Care Partner.
Communication Tips to Facilitate an Open Dialogue

Below are some general tips that may apply differently in different situations. Use good judgment to decide when and how to use them.

### Talk Tips

#### Be Unique
- Make it more than just another conversation
- Avoid asking questions the patient or care partner have answered before

#### Be Honest
- Sometimes it’s tempting to omit information, but providing good information helps the patient and care partner make good choices

#### Have a positive attitude
- A confrontational approach is less likely to help you elicit a quality response
- Be polite and leave a good impression

#### Stay Neutral
- Don’t judge or directly criticize

#### Avoid Interruptions
- This can upset the train of thought and response

#### Minimize Your Own Verbalization
- Ask questions clearly and concisely, and then let the person speak without adding anything additional

#### Be A Good Listener
- Learn to react silently as the subject talks instead of saying things like “uh-huh, right, I see,” use nods and facial expressions

#### Avoid Over-Direction
- Try not to give too many instructions or be too specific about what you want them to say. In most cases it’s better to let them speak freely

#### Show Empathy
- Often you will need to cover sensitive topics, show compassion without getting too emotional
- Ask for permission before asking difficult questions, for example, “Is it okay to talk about...?”

#### It’s Not About You
- Don’t talk about yourself or add your own opinion
- The patient is the one who the needs to be heard. When you finish your training discussions, put your notebook away and have an informal chat.
- If you missed a question in your conversation you may want to cover the topic in your next call or meeting with the patient
Patient Selection – Orientation

This section of Open Connection is designed to be used before training begins or during the patient’s orientation session. Below are examples of how you can welcome new patients to home hemodialysis with the NxStage System One and a few questions to ask them.

Sample Copy for Dialogue with Patient

Congratulations on your decision to take control of your health with more frequent home hemodialysis with the NxStage® System One™. Soon you may start experiencing some of the life-changing benefits of more frequent home hemodialysis. That being said, it’s important to remember that not all experiences are the same and your experience with more frequent home hemodialysis may be different.

The Home Team here congratulates you on taking this important step and wants you to have a successful training experience. I have a few questions for you that will help me, as a member of your Home Team, understand you and your health goals.
Questions to Ask During Orientation

How long have you been on dialysis?
What are your reasons for choosing home hemodialysis?
What expectations do you have about performing your treatment at home?
How does your family feel/deal with your chronic kidney disease?
Tell me what parts of your care you will do and what your home partner will do?
What’s on your bucket list? In other words, can you name 2 or 3 personal goals that you have?
What are 3 things that will help make your training a positive experience?
I’d like to share a list of things you will learn during your training:

You Will Need To Learn:

✔ How to prepare your home
✔ How to set up the equipment
✔ How to access your blood
✔ How to start, perform, and end your treatments
✔ How to deal with alarms and complications during your training and at home
✔ How to manage your supplies
✔ What to report to your health care team

Studies have shown that when patients do more for themselves they feel better, and their care partner may feel less stressed. As a patient, you may feel more in control of your treatments and your kidney disease when you do more for yourself.

Tools and Resources

Location: NxSTEPS Training Portal*
- HHD Patient Self-Assessment
- Patient Schedule
- Customization Tool

Location: NxSTEPS Quick Reference Guide Binder
- Patient and Care Partner Learning Checklist
- How do I get ready for home hemodialysis?

* The NxSTEPS Training Portal is an online resource, found at NxStage.com, for patients and care partners to access information

Reminder

Don’t forget to give your patient their copy of the Patient Training Schedule
Now that you have completed orientation with your patient and set expectations it’s important to reinforce the support and tools available to them. **The first week of training can be overwhelming for your patient so use this time to ease their worries and or frustrations.**

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**Sample Copy for Dialogue with Patient**

Congratulations on starting your training program on the NxStage System One. As you’ll see during training, we will cover key concepts related to the proper use and operation of the System One as well as a variety of other topics. NxStage recognizes that everyone is different, therefore; the program and tools will be tailored specifically to meet both you and your care partner’s needs. Your Home Team is here to support you during training and will make sure you, your care partner, and your family feel comfortable every step of the way.
WEEK 1: QUESTIONS TO ASK YOUR PATIENT

What was a day in your life like before dialysis?

Tell me your top two favorite things you like to do with family or friends.

What support networks do you have available to you? (friends, family, community)

What is important to you?

Tell me about your________________________? (This can be work, hobby, family, friends, or whatever they have said is most important to them)

Tools and Resources

Location: NxSTEPS Quick Reference Guide Binder

- How do I determine my treatment dose?
- How do I enter my treatment information?
- How do I maintain aseptic technique?
- How do I access my blood?

Reminder

Dont forget to complete the following documents:
- Patient and Care Partner Learning Checklist.
- What Motivates You?
With Week 1 complete, you now have more information on what’s important to your patient and care partner and what some of their goals are. **Start this week by openly talking about the implications of home hemodialysis on their schedule.** There are a lot of changes involved in performing treatments at home and it is good to listen and hear from them on what they believe their biggest challenges are and their action plan for overcoming them.

**Sample Copy for Dialogue with Patient**

Working through the training steps can be difficult. In addition to being asked to perform a variety of treatment tasks, the training schedule can also be a challenge. Some patients tell us that organizing their schedules has had a positive impact on their work, school, and home life.
WEEK 2: QUESTIONS TO ASK YOUR PATIENT

Describe what you think some of the biggest challenges are so far in your training.

If you had to make changes at home or work to manage your training schedule, describe how you would accomplish this change.

Tell me a few ways you think you can make changes easier for your care partner, family, or employer.

What do you think is going to be the hardest treatment task for you to do at home?

What ideas do you have that you would like to work into an action plan?

Tools and Resources

Location: NxSTEPS Training Portal
  ▪ Action Plan

Location: NxSTEPS Quick Reference Guide Binder
  ▪ How do I use the System One Cycler?
  ▪ How do I manage PureFlow?
  ▪ How do I recognize infection?
  ▪ How do I take precautions?

Reminder

Don’t forget to complete the Patient and Care Partner Learning Checklist.
Think back on your discussions with your patient and care partner during Week 2 regarding the training schedule. In Week 3 you may notice some patients are feeling the challenges and pressure often associated with the training schedule as it might be interfering with what they would have considered a “typical day”. Talk about these challenges and how training has changed their normal routine. **This week, reiterate that because there are a lot of changes and challenges happening it’s important to share those feelings with your training team and care partner.**
WEEK 3: QUESTIONS TO ASK YOUR PATIENT

What do you find the most challenging about fitting your training into your daily routine?

Describe how training has affected a typical day or evening, especially when you have other things in your schedule.

What are the 2 biggest challenges your care partner has had with the training schedule?

What are the 2 biggest challenges your family has had with the training schedule?

What can you do to make the schedule easier on your care partner and family?

Location: NxSTEPS Quick Reference Guide Binder
- How do I troubleshoot common alarms?
- How do I deal with the unusual?
- How do I recognize a problem?
- Are you Ready? Planning Guidebook for Non-Medical Emergencies

Reminder
Dont forget to complete the Patient and Care Partner Learning Checklist.
Begin Week 4 with a high note and celebrate your patient’s successes so far. It has been a month since your patient and care partner started training and they have had to work through some difficult timing and treatment challenges. This may be an emotional time for your patient and care partner so make sure to celebrate their successes in Week 4. Additionally, your patient and care partner will be in the final days of training so make sure to talk about their plans for their treatments at home. Have them talk about the room where they will perform their treatments and stress the importance of finding a place they feel comfortable.

Sample Copy for Dialogue with Patient

Congratulations, it has been a month since you have started training! We know how important space and environment are to feeling comfortable and to feeling well. Setting up your environment for success, wherever you are, is a really powerful tool.

Making some decisions on space, conditions, and supply locations, are some important tools that can help you get organized and feel at ease performing your treatments at home.
WEEK 4: QUESTIONS TO ASK YOUR PATIENT

Where are you planning to do your treatments?

Why did you pick that room/space?

Where are you planning to store your supplies?

Let's review the “How do I get ready for home hemodialysis” Quick Reference Guide, are there any questions you have?

Let's discuss when you are planning to do your first treatment at home and plan a visit.

Tools and Resources

Complete the following documents before the patient starts treatments at home next week:

- Patient and Care Partner Learning Checklist
- HHD Patient Self-Assessment
- Patient Certificate of Completion

Reminder

Dont forget to complete the following documents:
- Patient and Care Partner Learning Checklist.
- What Motivates You?
After Training, At Home

Now that your patient and care partner have completed training and are home with their System One, they may be feeling a little overwhelmed so it’s important to keep the dialogue going to let them know you are still there to help. **Schedule weekly check-ins with them over the phone to hear about how their treatments are going and address any fears and concerns they have being home.**

Sample Copy for Dialogue with Patient

Congratulations on your first week at home! I’m sure you have been experiencing a variety of emotions performing your treatments in your own home.

To help with that many people tell us that writing down their goals, challenges, and achievements, and keeping them where they can review them from time to time, helps them to deal with the new stresses of performing their treatments at home.
WEEK 1: QUESTIONS TO ASK YOUR PATIENT

Do you remember the goals we talked about when you started home dialysis training? Let’s review them.

What were your goals when we first started; have you met them? (If they have met a goal, make sure to congratulate them.)

Name 2 things that have gone really well for you and your care partner this week?

How did you celebrate that success with your care partner or family?

Remind patient and care partner about the NxSTEPS training portal to access and view On-line modules and Quick Reference Guides.
In the second week your patient and care partner are treating at home. They may have already experienced some difficult moments. Whether there was a machine alarm or caution, or a missed step, they may be feeling vulnerable in dealing with these unexpected issues. **When you speak to them this week make sure to listen to some of their difficulties and help them refer back to their action plan, create a new one for any particular problems and encourage them to use the NxSTEPS Patient Portal for tools and resources.**
WEEK 2: QUESTIONS TO ASK YOUR PATIENT

Tell me about anything that has not worked well for you since you started home treatments.

What is the single most challenging thing that has happened?

How could an action plan help you deal with that challenge?

Were there any alarm conditions that were a challenge during treatment? How did you address that?
Having spent the last two weeks at home with their NxStage System One, your patient and care partner have most likely had to overcome some challenging situations. From dealing with the unexpected issues or alarms to finding a schedule that works for them; they should hopefully be starting to find a routine and are beginning to feel more confident in performing their treatments at home. **Take time to talk with them about any treatment or social issues they have been experiencing with home hemodialysis.**
WEEK 3: QUESTIONS TO ASK YOUR PATIENT

Let’s go over the steps that you took to help overcome your challenges. (Review Action Plan)

In what ways have your family relationships or friendships changed since you began managing your treatment at home?

Describe any issues you are having with your relationships.

What support do you think would help you, and the important people in your life?

Location: NxSTEPS Training Portal

- How do I Deal With the Unusual?
- How do I Recognize a Problem?

Reminder

Have your patient talk to a patient advocate, social worker, or other patient mentors from their program.
Patients have let us know that part of the benefits of being at home is that they have more flexibility. They have control of when they want to dialyze which, may give them more time to do things they enjoy such as work, socialize, school, and hobbies. At Week 4 they should have established a routine at home and may find they have more energy to possibly get back to some of their hobbies or interests that they didn’t have time for while they were in-center. **Speak to them about their treatment schedule and what they do in their spare time.** Make sure to check-in with the patient and gauge whether or not they feel they have the time or energy to return to an interest or hobby and help them make an action plan to work towards those goals.
WEEK 4: QUESTIONS TO ASK YOUR PATIENT

Tell me how your social life has changed since you have been performing your treatments at home.

What activities are you missing in your life, due to your home treatment schedule?

Tell me what you would need to do to fit those activities back into your life?

What first “action step” would you include in your plan to fit a favorite activity back into your life?

Schedule monthly clinic visits with your patient and their care partner. Complete the HHD Patient Self-Assessment Form together.

Reminder
Last week when you connected with your patient and care partner, you focused on their social life and worked on an action plan to help them get back to the hobbies and activities they enjoyed. **Make sure to follow-up with them and see if they have taken any steps forward with adding activities back into their lives.** Many patients on more frequent therapy feel better and do get back to some of the “typical” activities and hobbies that they enjoyed prior to their diagnosis. Check-in with them and listen to their concerns and find out what is working and what isn’t.
WEEK 5: QUESTIONS TO ASK YOUR PATIENT

List all of the activities you have added back into your life, now that you can schedule your home treatments with more flexibility.

How did that work out for you? Describe what worked best to help you.

Tell me how it feels to be able to add this activity back into your life.

Remind your patient and their care partner to visit the NxSTEPS Training Portal for information and support.

In addition, check to see if a Mentor Program is available for them.
Many patients chose to go on home therapy with the NxStage System One because of the flexibility in dosing options available. With the ability to decide with their doctor and care team when, where, and how long they dialyze, patients have the option to choose a therapy that fits around their lifestyle. **In Week 6 make sure you connect with your patients about the flexibility of their therapy and if a treatment schedule isn’t working let them know there are other treatment schedules available, including nocturnal therapy.** While many patients begin their home treatments with more frequent therapy, nocturnal therapy may be a possible solution for your patient and care partner.
WEEK 6: QUESTIONS TO ASK YOUR PATIENT

- Now that you are performing your dialysis treatments at home, tell me 2 ways your treatment schedule has affected work, school, or your home routine.
- Were there any work, school, or family schedules that you had to adjust?
- Can you think of a good way to reorganize your treatment or schedule to make sure you meet your needs? Let’s use an Action Plan to achieve your needs.
- Give me 3 ideas for organizing your time.
- Let’s talk about some of the options you may have.
After discussing possible alternative options for your patient’s treatment schedule, make sure to follow-up and see if they were able to find a better fit. It’s important that while your patient is treating at home they feel comfortable and have developed a schedule that works for them. Many patients experience a number of clinical and lifestyle benefits with more frequent therapy on the NxStage System One but often the burden of therapy or establishing a new routine in the first few weeks being at home lead to patient or care partner burn-out and they return in-center. Make sure to take the time to work with your patient to understand the challenges of finding the correct treatment schedule and reinforce the importance of action planning to address these challenges.
WEEK 7: QUESTIONS TO ASK YOUR PATIENT

How have you been flexible or creative in adjusting your therapy to fit your needs, and the needs of your care partner or family?

Tell me about your care partner and how they are adjusting to your home hemodialysis schedule?

Describe 2 personal goals that may be achieved with the help of action planning.

Reminder

Ask patient about their Care Partner and offer yourself as a resource if they have any questions and concerns.
Financial stress affects more than just a patient’s or care partner’s wallet: It can have a ripple effect on their health and interpersonal relationships. **Take the time this week to talk to your patient and care partner on the financial stresses of beginning home hemodialysis treatments.** Make sure to help them develop an action plan on how to deal with these financial issues.
WEEK 8: QUESTIONS TO ASK YOUR PATIENT

Is it okay if I ask you how your health has affected your home finances? (Monetary challenges since being on dialysis)

Tell me what 2 things come to mind as your 2 most difficult adjustments.

How can I, or your care team, help you with these challenges?

What sort of action plan would you like to put together with the home team social worker to help you target some of these challenges?

Tools and Resources

Location: NxSTEPS Training Portal
- Action Plan

Reminder

Encourage monthly clinic visit and meeting with Social Worker to review progress to date. Complete the HHD Patient Self-Assessment Form together. During this visit speak with patient and care partner separately to discuss any challenges they are facing.
It has been over two months since your patient and care partner began their treatments with the NxStage System One at home. **Make sure during this week’s discussion to congratulate them on this tremendous accomplishment.** There are a lot of changes and challenges your patient and care partner have overcome to reach this point and it is important to recognize the work that they have done to get here. Use this week to discuss the changes in their life since beginning home hemodialysis treatments.
WEEK 9: QUESTIONS TO ASK YOUR PATIENT

What changes have you noticed in yourself since starting home treatment? (lifestyle, mood, etc).

Tell me about one activity you have been able to incorporate back into your life since starting Home Hemodialysis.

Tools and Resources

Location: Open Connection Booklet
- Thank You Postcard

Reminder

Have your patients send their physician a Thank You postcard showing them how much they appreciate their help in getting them home.
From day one of training with the NxStage System One, your patient and care partner have been learning how to adapt to the requirements and changes home hemodialysis might make on their lives. Between financial implications to changes in family or friendship dynamics, they have been learning to adapt and adjust as they need, to fit home dialysis into their schedules. **Take time to talk about these adjustments, what worked for them, and how they have tackled these issues to fit their home treatments into their life.**
WEEK 10: QUESTIONS TO ASK YOUR PATIENT

What adjustments have you made in who does what in your home routine?

Tell me how you made the change?

Describe any activities or personal time you have given up since you have been home on dialysis.

Tell me what you would like to do to help your care partner.
As the three month mark approaches, use this time to talk to your patient and care partner about how far they have come with the home hemodialysis therapy. Remind them of the changes and challenges they have had to overcome. The first 90 days for patients on home hemodialysis therapy is crucial to developing a routine and getting used to the new “normal”. **Remind them of all they have accomplished and continue to work with them to find ways to make their treatments easier on their lifestyles, families, and care partners.**
WEEK 11: QUESTIONS TO ASK YOUR PATIENT

Tell me how dialysis at home is fitting into your life?
What have you done to make dialysis easier?
How have you made progress towards your personal and health goals?

Encourage your patient and care partner to tell their story. Ask if they would be interested in mentoring others considering Home Hemodialysis?
Making it through the first twelve weeks of home hemodialysis is a huge accomplishment for your patient and care partner. Congratulate them on their progress and how far they have come. **Make sure to talk about the benefits of home hemodialysis therapy that they may be experiencing and continue to keep the lines of communication open as they move on with their therapy.**

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**Sample Copy for Dialogue with Patient**

Congratulations on a job well done!

By now you may be experiencing some of the many benefits of performing more frequent home hemodialysis.

Maybe you’ve been able to spend more time with family and friends or even taken your System One traveling with you. You have taken control of your healthcare and your life. Don’t forget to celebrate your successes with your care partner and family.
Congratulate patient on making it through the 1st 90 days at home and offer continued support if needed.

WEEK 12: QUESTIONS TO ASK YOUR PATIENT

Did you manage to overcome the challenge we talked about last week?

Can you tell me how things have improved?

Describe any challenges you see surfacing that may become a problem.
Thank You

For All You Do!
Despite the health benefits that more frequent home hemodialysis may provide to those with chronic kidney disease, this form of therapy is not for everyone. Home hemodialysis with the NxStage System One requires a patient and partner who are committed to being trained on and following the guidelines for proper system operation.

The reported benefits of home hemodialysis may not be experienced by all patients.

The NxStage System One is a prescription device and, like all medical devices, involves some risks. The risks associated with hemodialysis treatments in any environment include, but are not limited to, high blood pressure, fluid overload, low blood pressure, heart-related issues, and vascular access complications. The medical devices used in hemodialysis therapies may add additional risks including air entering the bloodstream, and blood loss due to clotting or accidental disconnection of the blood tubing set. Patients should consult with their doctor to understand the risks and responsibilities of home and/or more frequent hemodialysis using the NxStage System One.

Certain risks are unique to the home. Treatments at home are done without the presence of medical personnel and on-site technical support. Patients and their partners must be trained on what to do and how to get medical or technical help if needed.

Certain risks associated with hemodialysis treatment are increased when performing nocturnal therapy due to the length of treatment time and because therapy is performed while the patient and care partner are sleeping. These risks include, but are not limited to, blood access disconnects and blood loss during sleep, blood clotting due to slower blood flow or increased treatment time or both, and delayed response to alarms when waking from sleep. Patients should consult with their physician to understand the risks and responsibilities associated with home nocturnal hemodialysis using the NxStage System One.