

# Home Dialysis Heroes: A Home Dialysis Patient Peer Program Guide

## What Is a Home Dialysis Patient Peer Program?

A Home Dialysis Patient Peer Program is a program that connects patients receiving home dialysis with in-center hemodialysis patient. This connection supports a journey toward a home treatment option. Unlike peer mentoring, Home Dialysis Heroes are local, goal-focused, may include family and caregiver interaction and are paired with local dialysis patients. The Home Dialysis Heroes Program is goal-focused, can include family and caregiver interaction, and includes multiple ways for Home Dialysis Heroes and Dialysis Peers to connect.

## Who Is Involved?

- Home Programs: Identify potential home dialyzers to be heroes for in-center Dialysis Peers who are considering transitioning to a home dialysis therapy.
- Dialysis Centers: Promote the program to people receiving in-center dialysis and welcome Home Dialysis Heroes virtually or into the facility's activities and space.
- ESRD Networks: Promote the program and share resources with in-center dialysis facilities and home programs.
- Home Dialysis Heroes: Provide emotional support and practical tips from their own home dialysis experience to guide their Dialysis Peer toward a home treatment option.
- Dialysis Peers: Engage with their Home Dialysis Hero and welcome support on their journey to toward home dialysis.

## What's Included in This Guide?

- Introduction
- ESRD Network Role
- Dialysis Facility Role
- Home Program Role
- The Home Dialysis Hero Role
- The Dialysis Peer Role
- Multiple Ways to Connect



## Program Goals

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Encourage patients already doing home dialysis to share their “I did it and you can too” mindset to inspire more referrals to a home treatment option.

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Talk about the practicality and benefits of home dialysis so that more patients transition to and stay on home dialysis.

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Introduce home treatments as a viable treatment plan for new patients and for those who have been on in-center hemodialysis for a longer period.

# *We're Better Together*

Inform | Inspire | Innovate



## **Who Are Home Dialysis Heroes and What Can They Do?**

Home Dialysis Heroes are people that perform dialysis treatments at home. They provide emotional support and practical information to an in-center hemodialysis patient. Through sharing their experience, including preparing for home dialysis, selecting the best treatment option for themselves, and the benefits of dialyzing at home, Home Dialysis Heroes can support in-center dialysis patients in their dialysis choice. Home Dialysis Heroes are paired one-on-one with people receiving in-center dialysis treatments. Home Dialysis Heroes *do not* offer medical advice but are encouraged to share their firsthand experience in doing dialysis at home with their Dialysis Peer.

## **Should I Be a Home Dialysis Hero?**

As a Home Dialysis Hero, you know better than anyone else what it is like to do dialysis at home, how to ensure your safety, who to contact for support, and the benefits of doing dialysis on your schedule at home. Share your experience and expertise by volunteering as a Home Dialysis Hero. Be a voice to help someone who is currently receiving in-center dialysis make the choice to move to a home dialysis treatment option.

## **Would a Home Dialysis Hero Benefit Me?**

As a person on dialysis, understanding how to cope with kidney disease can be overwhelming. There are many people who have been in your shoes. Connecting with someone is doing dialysis at home to learn about how the choice to pursue dialysis at home can be a positive life-changing experience. A Home Dialysis Hero can also support you by answering your questions, connecting you with resources, and even providing emotional support on tough days.

# Who Would Be a Great Home Dialysis Hero or Dialysis Peer?

## Suggested Criteria for a Home Dialysis Hero

- Performs peritoneal or hemodialysis at home
- Proud of transitioning to home dialysis and eager to share their story to inspire Dialysis Peers to choose a home treatment option that's right for them
- Familiar with the terms, process, and benefits of home dialysis
- Well-adapted to the challenges faced by Dialysis Peers
- Effective communicator with empathy skills
- A desire to support Dialysis Peers in their journey with kidney disease
- Schedule flexibility to be available for their Dialysis Peer by telephone or other virtual ways, or in-person if program participants are located near each other and it is safe to meet in-person
- A trusted confidant for their Dialysis Peer

## Suggested Criteria for a Dialysis Peer

- A person who is receiving in-center hemodialysis
- Someone who is interested in learning about home dialysis treatment options, or a person who has already been referred to a home program and is interested in more about their options before they begin training
- An individual who is interested in learning about the benefits of home dialysis, including diet and exercise restrictions, caregiver requirements, adaptations to the home and receiving and storing supplies.
- Someone who is engaged and eager to be more involved in their care and participates in patient activities at their facility, such as education, lobby days, etc.

Research racial and ethnic disparities in the rates of people on home dialysis modalities<sup>1</sup>. Be sure that Home Heroes represent the demographic make-up of the ESRD Network patient population. If relevant in your Network service area, share these disparities with your Home Hero and match them with someone of a similar background and/or living situation.



“I learned how easy my entire family could be trained, it was much easier than I first thought.”

**HOME DIALYZER**  
**2020 NPFE-LAN**  
**Patient Subject Matter Expert**

<sup>1</sup> Kidney Med Vol 2 | Issue 2 | March/April 2020; Daniel E. Weiner, MD, MS, and Klemens B. Meyer, MD.

# ESRD Network Role

## How to Contribute

The role of the ESRD Network is to promote the Home Dialysis Hero Program with in-center dialysis facilities and home programs within the service area. The Network should expect to coordinate with participating in-center dialysis facilities and home programs to introduce the program, share resources, track program success, assist when needed, and facilitate spreading program success stories.

## How It Works

- 1 Introduce the program to in-center dialysis facilities and home programs in their service area
- 2 Recruit in-center dialysis facilities and home programs to participate in the program
- 3 Partner with in-center dialysis facilities and home programs to host a program kick-off event and invite staff to attend
- 4 Provide assistance when needed, and share success stories in the Network provider and patient newsletter
- 5 Celebrate program accomplishments
- 6 Be a supporter by promoting the program within your Patient Advisory Council and throughout your service area

## Implementation Recommendations

- Prepare an introductory program flyer to share with in-center dialysis facilities and home programs
- Collaborate with in-center dialysis facilities and home programs to recruit Home Dialysis Heroes and Dialysis Peers
- Identify a in-center dialysis facility and home program staff member to lead the program and connect Home Dialysis Heroes with Dialysis Peers
- Recommend that in-center dialysis facilities and home programs coordinate the pairing of Dialysis Peers and Home Dialysis Heroes
- Share kick-off materials to educate Home Dialysis Heroes and Dialysis Peers on their roles and program expectations
- Provide support by scheduling regular check-ins with in-center dialysis facilities and home programs
- Start small and expand incrementally based on success stories
- Celebrate successes and continue to expand program reach

## How will your Network benefit?

- + **Creates the opportunity** to increase patient referrals to home dialysis and achieve the national goals of Advancing American Kidney Health
- + **Improves patient engagement** and offers the opportunity for the Network to recruit new patients for their Patient Advisory Council

- + **Boosts mental health for patients** through connecting with their Network to achieve the goal of referring more patients to home dialysis
- + **Supports a culture of patient-centered care** by improving patients' quality of life and healthcare outcomes

# In-center Dialysis Facility Role

## *How to Contribute*

Home Dialysis Heroes work closely with FPRs. However, unlike an FPR or even a peer mentor, their focus is being available to a larger group during activities like lobby days, patient education events, and virtual support group meetings to share the benefits of home dialysis. Dialysis Peers at your center will gain valuable knowledge and awareness from a Home Dialysis Hero with the aim of referring their in-center dialysis peer to a home program professional to learn more about their options for home dialysis.

## *How It Works*

- 1 Be introduced to the program and gain an understanding of your facility's involvement and opportunity to increase the use of home dialysis
- 2 Partner with local home programs to identify, match, and connect the Home Dialysis Hero to one of your patients receiving dialysis
- 3 Host a kick-off event virtually or at your facility to educate Dialysis Peers on their roles and program expectations
- 4 Welcome Home Dialysis Heroes and Dialysis Peers to meet at your facility and provide support when needed
- 5 Celebrate program accomplishments
- 6 Sustain the program by being a program supporter and promoting the program success at your facility

## **How will your facility benefit?**

- + **Increases** the facility rate of referral to home dialysis and supports the national goals of Advancing American Kidney Health
- + **Improves patient engagement** by collaborating with the facility patient representative to advance facility and national goals

## *Implementation Recommendations*

- Utilize introductory materials to announce the program and create awareness
- Identify an in-center dialysis facility staff member to lead the program and connect Home Dialysis Heroes with Dialysis Peers
- Share kick-off materials to educate Dialysis Peers on their roles and the program expectations
- Introduce Home Dialysis Heroes to your Dialysis Peers as a knowledge resource and support system
- Establish a way for Home Dialysis Heroes and Dialysis Peers to meet virtually or in-person
- Provide the opportunity for Home Dialysis Heroes and Dialysis Peers to share their program experience during lobby days
- Offer support by scheduling regular check-ins with Dialysis Peers engaged in the program and inform your ESRD Network of program successes
- Start small and expand incrementally based on success stories
- Celebrate successes and continue to expand program reach

- + **Creates a community** by supporting the development of relationships amongst past and present patients
- + **Provides additional home dialysis patient education** through patient success stories and lived experience to increase referrals to home programs



# Home Dialysis Program Role

## *How to Contribute*

Support the Home Dialysis Hero Peer Program by introducing the program at your center, identifying people who are interested in being a Home Dialysis Hero, hosting program meetings at your site, and celebrating program accomplishments. Collaborate with in-center dialysis centers and your ESRD Network to promote the program beyond your organization.

## *How It Works*

- 1 Identify and recruit Home Dialysis Heroes and notify your Network of patients who are interested in joining the program
- 2 Work closely with local in-center dialysis facilities to connect your Home Dialysis Hero with a Dialysis Peer
- 3 Host an orientation kick-off to teach Home Dialysis Heroes about their role and program expectations
- 4 Support the program by collaborating with local in-center dialysis facilities and your ESRD Network
- 5 Provide basic resources about the benefits of home dialysis for your home program Hero to share with their Dialysis Peer
- 6 Celebrate the program success with your local Network, dialysis facilities, Heroes, and Dialysis Peers

## *Implementation Recommendations*

- Use introductory materials to announce the program and create awareness
- Identify a home program staff member to lead the program and connect Home Dialysis Heroes with Dialysis Peers
- Share kick-off materials to educate Home Dialysis Heroes on their role and program expectations
- Provide the opportunity for Home Dialysis Heroes and Dialysis Peers to share their program experience during in-center new patient orientation
- Establish a way for Home Dialysis Heroes and Dialysis Peers to meet virtually in-person or at their dialysis facility when safe to do so
- Offer support by scheduling regular check-ins with Home Dialysis Heroes engaged in the program
- Start small and expand incrementally based on success stories
- Celebrate successes and continue to expand program reach

### **How will your home program benefit?**

- + **Increases patient access** to home dialysis treatment options available in your home program and supports the national goal of Advancing American Kidney Health
- + **Improves the home dialysis patients'** focus on successfully sustaining their home treatment option

- + **Creates a community** by supporting the development of relationships amongst present and potential future patients
- + **Reinforces and supplements home program education** for in-center Dialysis Peers and improves the opportunity of referrals to home dialysis

# Home Dialysis Hero Role

## How to Contribute

As someone who's is receiving dialysis, you are familiar with the ups and downs of kidney disease. Now that you are doing dialysis at home, you can use this experience to share the benefits of doing dialysis at home to guide a Dialysis Peer along a familiar journey.

## How It Works

- 1 Sign up to be a Home Dialysis Hero through your home dialysis center
- 2 Work closely with your ESRD Network to connect with an in-center dialysis facility and a Dialysis Peer
- 3 Attend a kick-off meeting to learn about your role and program expectations
- 4 Support your Dialysis Peer partner through activities that interest you both and fit your schedules
- 5 Provide motivation and encouragement to your Dialysis Peer by sharing your home dialysis experience
- 6 Celebrate your accomplishments and successes

## How to Be a Trusted Partner

### How you can help your Dialysis Peer:

- Share insights from your personal experience with dialyzing at home
- Refer your Dialysis Peer to their care team when asked medical questions
- Maintain patient confidentiality
- Provide reassurance and be an empathetic listener
- Encourage Dialysis Peers to remain engaged in their plan of care, maintain doctor appointments, and stay active on the transplant waitlist
- Offer encouragement after a discouraging day and help them to thrive in their circumstances
- Meet virtually at a time that is convenient for both people

### What you should **not** do for your Dialysis Peer:

- Give any medical advice, including diet options
- Handle their grievances or challenges, always refer them to their social worker or facility administrator
- Borrow or loan money
- Invade their privacy, personal space, or breach their confidentiality

## How will the Home Dialysis Hero benefit?

- + **Remains motivated in their treatment** by staying engaged in their plan of care and up-to-date on the best treatment opportunities and practices
- + **Expands their leadership skills** by sharing knowledge about home dialysis and persuading others to go on that same journey

- + **Improves problem-solving and communication skills** by clearly sharing their own experiences and assisting their Dialysis Peers in achieving their treatment goals
- + **Contributes to something larger than themselves** by supporting the overall quality of life for people with kidney disease

# Dialysis Peer Role

## How to Contribute

Meet with your care team to hear about how to connect with a Home Dialysis Hero and learn how home dialysis improved their quality of life and can help you. Kidney disease can be overwhelming, but there are many people who have been in your shoes and are willing to be your support peer. Your Home Dialysis Hero can also offer support by answering your questions, connecting you with resources, and even providing emotional support on tough days.

## How it Works

- 1 Talk with your care team about the program and sign up to be a Dialysis Peer to learn more about home dialysis options
- 2 Your facility will help you get matched and connected with a Home Dialysis Hero
- 3 Attend a program kick-off to learn about ways in which a Home Dialysis Hero can support you
- 4 Seek guidance from your Home Dialysis Hero, listen to their story, and learn from their experiences
- 5 Commit to a positive treatment journey by remaining engaged in your dialysis treatment plan and involved in the program
- 6 Celebrate accomplishments in achieving your treatment goals and share your success story

## How will the Dialysis Peer benefit?

- + **Increases their knowledge of kidney disease treatment options and benefits** as your Home Dialysis Hero shares insights from their own experience receiving dialysis at home
- + **Encourages dialysis peers to be an advocate for their own health** and empowers them to become aware of the steps required to transition to home dialysis

## How a Home Dialysis Hero Can Help You

### Your Home Dialysis Hero can:

- Share knowledge and insights from their personal experience with receiving dialysis at home
- Be a strong source of support by listening to your concerns
- Refer you to members of your care team related to medical questions
- Provide encouragement and guidance

### What your Home Dialysis Heroes should **not** do for you:

- Give medical advice, like changing your diet or medication
- Invade privacy and personal boundaries or breach your confidentiality
- Handle grievances or complaints
- Borrow or loan money

### Sample activities that you can do together:

- When safe to do so, visit your local library for social and educational events to remain active
- Team-up and share your experience at your facility lobby day
- Connect by phone to share times of joy or challenging days

- + **Reduces communication gaps with staff** by connecting peers to the appropriate resources and experts when there are questions or concerns
- + **Provides emotional and social support** and encourages peers to share their feelings and introduces them to a support system within the home program



# Multiple Ways For Home Dialysis Heroes and Dialysis Peers to Connect

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*Here are some tips for how to connect virtually and in-person. Each method offers unique features, pick which one works best for you!*

## Telephone & Text Messages

Exchange phone numbers! The telephone is a great way for Home Dialysis Heroes and Dialysis Peers to connect with each other. Agree upon a time to talk with each other, decide who will call who, be sure to put a reminder on your calendar, and connect with each other at the scheduled appointment time.

## Google Hangouts

The [Google Hangouts](#) app, available for both iOS and Android smartphones and mobile devices, is easy to install and use for free voice and video calling and video conferencing. It's available for Windows and Mac desktop and laptop computers as well, so it synchronizes across all your devices. You can even use Hangouts for texting.

## Messenger Apps

Use instant messaging! Apps like [WhatsApp](#) or [Facebook Messenger](#) are mobile messaging apps used for instant messaging, sharing photos, videos, audio recordings and for group chats. The apps are usually free to download, can be used to communicate on your phone, but can also sync to your computer or tablet.

## Google Duo

[Google Duo](#) is a free video chat mobile app that enables one-to-one video and voice calls across both iOS and Android devices. Simply download the Duo app and get started using video calling regardless of what kind of smart phone you have. It's also available via Google's chrome web browser on desktop and laptop computers.

## FaceTime

[FaceTime](#) is perfect for seeing and hearing people over the phone. FaceTime is exclusive to Apple, so you will both need an iPhone, iPad, iPod touch, or Mac to use this service. The good thing about FaceTime is that you can use WiFi when calling, saving minutes on your cellular data plan.

## In-Person

Talk with your dialysis facility and transplant center about when Home Dialysis Heroes and Dialysis Peers can meet at the dialysis facility or even at the transplant center if the partners are both near the transplant center. Heroes and Dialysis Peers may also choose to meet at their local church, favorite kidney diet-friendly eatery, local community center, or a mutually agreed upon location.

## Email

Exchange email addresses! Email is another way to stay in touch with each other, especially if you would like to share information and resources that can be found in the internet. Email is also a good way to connect with each other before or after your agreed upon time to meet.





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