

Getting Back to Me: A Goal-Setting Journey

From the End Stage Renal Disease (ESRD)

National Coordinating Center (NCC)

National Patient and Family Engagement Learning and
Action Network (NPFE-LAN)

Patient-Selected Topic Affinity Group



Table of Contents

Introduction.....	3
Focus on What’s Important to You.....	4
Step 1: Plan Your Goal-Setting Trip.....	6
Step 2: How Will I Get There?.....	8
Step 3: Set the Speed.....	10
Step 4: Who Can Help Me Get There?...	12
Notes.....	14
Draw What Success Looks Like to You... 	15

Introduction

Your emotional well-being is important. Kidney disease is life altering, but not life defining.

This workbook was developed by a group of kidney patients and family members who have felt the impact of this diagnosis on their overall emotional wellbeing. Caught in a world of uncertainty, they used various coping strategies to move forward. Through many heart-felt conversations and sharing of personal journeys, a common strategy formed—restoring hope and dignity through goal setting.



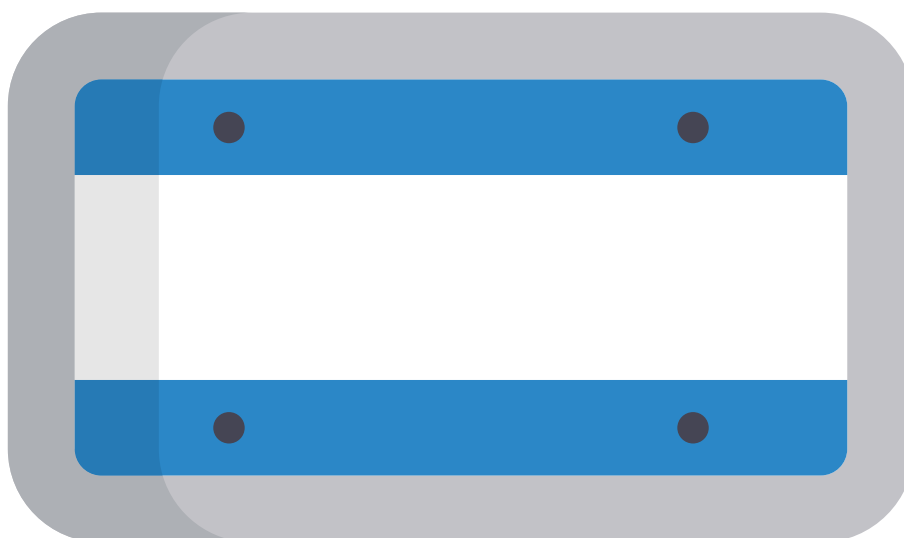
“Goal setting helped me see dialysis as giving me back my life and not taking my life away.”

—Donna, In-Center Dialysis Patient, FL

You Are Invited

The group of individuals who created this booklet are members of the NPFE-LAN Patient-Selected Topic Affinity Group. They invite you to take your own journey to discover your strengths by defining your goals. It’s a passage that can strengthen your emotional well-being, restore your dignity, and lead you to where you want to be.

This Workbook Belongs to:



Focus on What's Important to You



As you prepare to set your goals, take time to think about what's important to you. Consider the following questions to get you started:

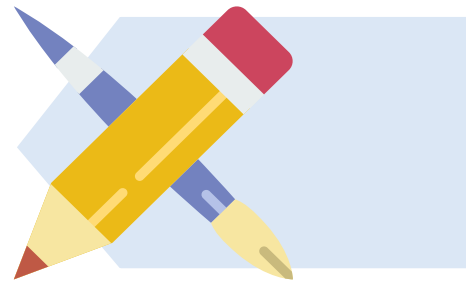
- What interests me?
- What are the most important reasons for making a change?
- How might my life be better if I made a change?
- Is this goal for me or am I doing this for someone else?

Example:

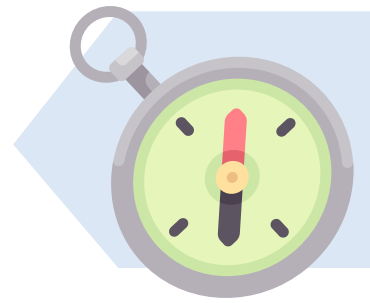
- Staying busy.
- My reasons: Support my family, steady income
- More independence.
- I want to do this!

My Thought Space:

Draw Your Thoughts



Step 1: Plan Your Goal-Setting Trip



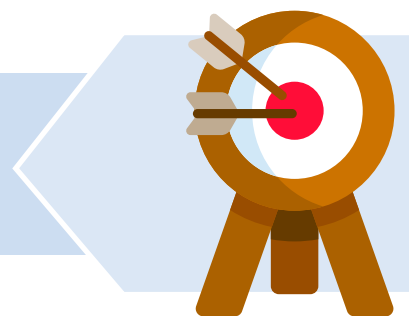
Ask yourself:

- What do I want to achieve?
- What's the benefit of achieving this goal?
- Is there anyone I should ask to be involved to provide support or help me reach the goal?

Example:

- Independence may mean trying something new.
- Talk to my social worker about where to start.
- My goal is to train for and get a new job!

On a scale of 1 to 10, with 10 being the most, how much do I want to reach this goal?



1 2 3 4 5 6 7 8 9 10



“The first step I take when setting a goal is to write it down. I make it specific and then break it down.”

—Jean, Transplant Recipient, FL

My Work Space: What Am I Doing for Step 1?

Use the space below to write or draw your idea.

Step 2: How Will I Get There?



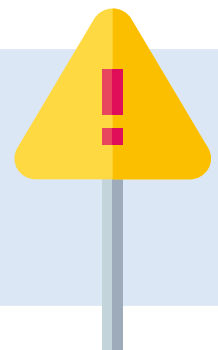
Ask yourself:

- Do I know what it will take to reach this goal?
- Do I have what it takes to reach this goal? If not, can I get what is needed?
- Do I have the resources needed to reach this goal? If not, can I get them?
- What barriers might slow me down from reaching this goal?

Example:

- I need to find out what skills I'll need to learn for my new job.
- My social worker will help me find the resources to learn new skills.
- Ticket to Work Program is an option.

Speedbumps that can get in my way and how I plan to handle each one:



Ex. Need to learn new skills



Ex. Research classes I can take



“I always plan for hurdles or obstacles. I consider them opportunities to learn and not as negatives.”

— Lonnie, In-Center Dialysis Patient, GA

My Work Space: What Am I Doing for Step 2?

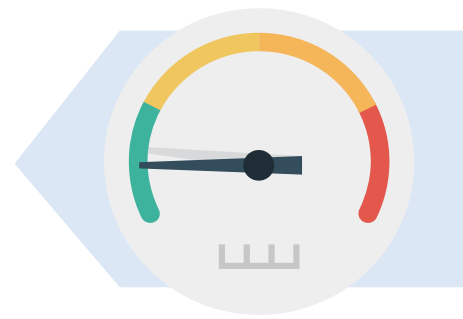
Use the space below to write or draw your idea.



“I use visualization with my goals. It helps me define the details. When I have a setback, visualization helps me believe the outcome is possible.”

—Wendy, In-Center Dialysis Patient, MA

Step 3: Set the Speed



Ask yourself:

- When am I going to start working on my goal?
- When do I want to reach this goal? Or how do I want this goal to look when it is complete?
- How will I know I've met my goal?
- Is my goal realistic?

Example:

- Talk to my social worker at the clinic next week about the Ticket to Work program.
- Create a timeline for meeting my goal.
- I will have achieved my goal when I am working!
- Make this happen in a year!

If my plan doesn't work, what will I do?



Example: Adjust as needed and learn from it!

My Work Space: What Am I Doing for Step 3?

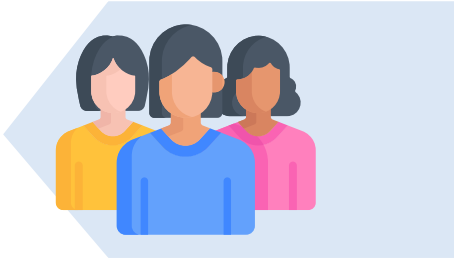
Use the space below to write or draw your idea.



“I create very specific goals, but I keep them simple. As I work toward the goal, what needs to be done always becomes clearer.”

—Doris, Transplant Recipient, CA

Step 4: Who Can Help Me Get There?



Ask yourself:

- Who can help me stay on target as I work toward my goal?
- How am I going to monitor my progress?
- How will I know if I need to make changes in my plan or goal?

Example:

— My social worker → Can help keep me on track!

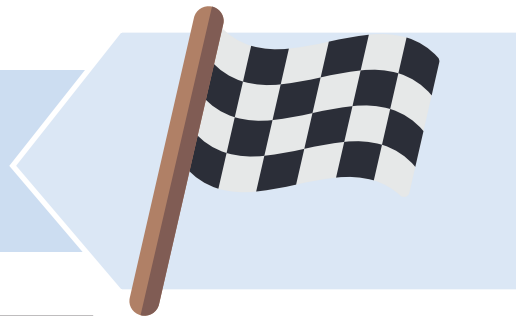
— My friend, Anne → Can help keep me on track!

— Keep an eye on my timeline and steps to meet my goal.

I need to remember—
It's okay to change or update my goals as I go along.
Nothing is set in stone.

A large, light-colored paper graphic with a wavy bottom edge and two brown corner tabs. It contains handwritten-style text and arrows pointing from the first two lines to the phrase 'Can help keep me on track!'.

What steps will I take to meet my goal?



<input type="checkbox"/>	_____	<input type="checkbox"/>	_____
<input type="checkbox"/>	_____	<input type="checkbox"/>	_____
<input type="checkbox"/>	_____	<input type="checkbox"/>	_____
<input type="checkbox"/>	_____	<input type="checkbox"/>	_____

My Work Space: What Am I Doing for Step 4?

Use the space below to write or draw your idea.

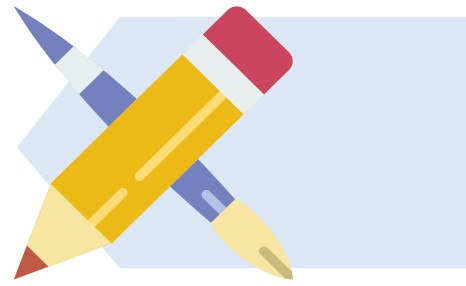


“I share my goal with someone who can help keep me on task and ask me how I’m doing with reaching my goal. I also review my steps regularly to see how I’m doing and if I need to make changes.”

—Tamiko, Home Dialysis Patient, AL

Notes:

Draw What Success Looks Like to You



Who We Are

The NPFE-LAN Patient-Selected Topic Affinity Group is part of the ESRD NCC. Its objective is for Network and NCC staff, providers, and stakeholders to partner with patient, family, and caregiver subject matter experts (SMEs) to enhance national quality improvement programs. This is accomplished by bringing together participants from all 18 ESRD Network regions to discuss and achieve patient-led initiatives.

The ESRD NCC believes that inclusion of the patient voice is essential to improved quality of life and quality of care for all ESRD patients, and that the Affinity Groups create opportunities for in-depth learning, problem solving, and achievement of patient-driven goals for quality improvement at the national level.

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