

MYLIFE TOOL

LIVING WITH LONG COVID

MY JOURNEY

INTRODUCTION





Living with long covid... ...is a journey

We are all at a different stage on the journey.

There is no right or wrong route and everyone's journey will take a different length of time. You might get stuck along the way, get lost or even travel backwards. You might like to take someone with you on the journey for support.

It is about working out what is helpful for you. This is an ongoing process. It is not something that happens overnight and it is not something that you achieve and never have to think about again. You may need to adapt or revisit your situation. Reflecting on what does and does not work for you can help you to do this.

The aim of this tool is to make your journey feel more manageable. You can use this tool at any point in your journey. You might not use it regularly but you can always come back to it when you need to.

It was designed by people living with long-term conditions and long covid.

You should approach this from your own perspective: something that fits with your life, your aims and your needs.

THIS TOOL

This tool is split into three parts:

MY JOURNEY

MY SCRAPBOOK

MY TOOLBOX

You can use this tool on your own or you might prefer to work through it with someone you trust. This introduction contains some activities to help you think about how you can get the most out of this tool.

The scrapbook is a tool to help you think about what is important to you, what you value and what you want to achieve. Being creative can also help you to cope with your condition.

Your tool box contains a range of tools for you to use. You can dip in and out of this toolbox as little or as often as you like. It is not about starting at one point and making it to the end. You can do it in any order you like. Find the tools that work for you and come back to them as often as you like.

MyLifeTool is also available online at www.mylifetool.co.uk if you need extra copies of the tools.

"It's a tool for life. It has helped me to learn about myself and improve on things and get more out of my life"

There is no end point to this tool. It is designed to help you reflect on your journey, so it is important that you take time to come back to each tool you work through to see how you are progressing on your journey.

Three booklets make up your Toolbox:

BOOK ONE
Embracing my body

BOOK TWO
Me and long covid

BOOK THREE
Connecting with others

WHERE AM I NOW?

Before you start using this tool, we recommend completing this short quiz. It will help you to think about where you are on your journey at this point in time. It will give you some ideas on how you might want to use this tool to help you move to a better place.

You might find it useful to come back to this quiz at different points in your journey to see if the tool is working for you.

Work out your total score by turning your answers into points and adding them together.

At this point in time...	Yes	Maybe	No
...do you think you need to change anything?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...do you accept that you have long covid?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...do you know how to change?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...do you treat your body like a loved one that you care about?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...do you see yourself positively?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...have any negative feelings that you might have about the long-term nature of your condition, now gone (e.g. anger, confusion, upset, etc)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...do you feel you have support?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...are you taking responsibility for your own health, whilst making the most of advice and support from relevant health professionals?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...are you able to maintain your life values?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TOTALS			

YOUR TOTALS

3 Yes answers get 3 points each

2 Maybe answers get 2 points each

1 No answers get 1 point each

YOUR TOTALS	Yes	Maybe	No
Number of questions answered...			
Answers into points...			

21 to 27

You are in the latter stages of your journey at this point in time but your journey is likely to change in the future. You may need to adapt your strategies or find new ones. You might find it useful to look at the resilience and approaching challenges tools in booklet two, focusing on resilience, approaching challenges and exploring things that are important to you.

15 to 20

You are making progress in your journey. You might find it helpful to look at the life wheel on page 6 of this booklet. It will help you to think about the areas you need to focus on right now.

9 to 14

You are in the early stages of your journey. You might find it useful to work through this tool one booklet at a time, starting with booklet one.

YOUR LIFE WHEEL

This tool can help you on your journey. Think about how comfortable you are in each area of the life wheel. Using this tool can help you work out the areas you are less comfortable with. Put a mark on the dotted line in each area that represents how comfortable you are with that area. The more comfortable you are, the closer to the outside of the circle you can put your mark.

Once you have identified which areas you are less comfortable with,

choose one area to start with and work through the booklet for that area. It is important to come back to this wheel regularly to see your progress.

During your journey you may find that you become less comfortable in some areas - this is normal.

If you come back to this tool regularly, you will be able to identify areas that need more attention and see your progress in other areas.

Me and long covid

I am comfortable...

- that long covid does not define me
- dealing with challenges
- that I appreciate my achievements

Embracing my body

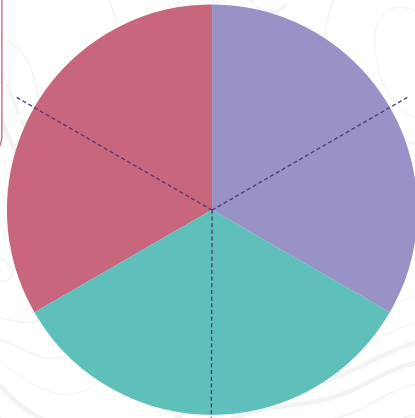
I am comfortable...

- that I know what my body is capable of doing
- with my pacing and coping strategies

Connecting with others

I am comfortable...

- communicating my needs to others
- reaching out to people



You can use this space to reflect on your journey by keeping a log of your experiences of using each booklet.

What can I do next?																				
What did I learn from doing these activities?																				
What activities have I tried?																				
What areas can I work on?																				
Date																				

MAKING CHANGES

Think about what might be helpful to change right now.

It could be that you need to make more time for rest, you need to start telling others about your condition, or even start being more kind to yourself and recognise your achievements.

List a few things you need to change Put them in order of priority.

MY REWARDS

When you have achieved your change, reward yourself.

Think of rewards: things that don't cost very much and that give you joy. Things like taking some time out for you, buying yourself a bunch of flowers etc. This tool has no end point, so once you have achieved your change, go back to your list and work on the next change.

List some things you can reward yourself with when you achieve change.

Choose one to work on first.

THE SILVER LINING

What people like you say about change...

Broken Cogs by Gordon Williams

For 38 years I was a cog in society's machine. Over time some of my cogs broke and I didn't fit the machine anymore. I found myself removed and put aside, broken and useless, a spare part that didn't fit.

Not wanting to be useless and wanting to be a working part and started to recycle myself. I am becoming a new part in the machine not as big, less significant but a working part none the less.

Since I broke I have met many other broken cogs. Whether they have realised it or not they have recycled too and are parts in the machine again just in different places.

So to all my fellow recycled cogs, society may not see where we fit, but we do and that's what matters most. So however you do it keep on turning!

"How do you cope?"

"how do you manage?"

"how do you do it?"

...really everybody has to find their own recipe
...to be active in their condition"

"At the end of the day, you'll find a route through this, to get support and find support and indeed, give support"

OUR TEAM

This tool would not exist without the work of our team of people living with long covid and long-term conditions and our researchers...

Stephanie Kiling

Cheryl Delisser

Lisa Newson

Dorothy Newbury-Birch

Sue Becker

Jill Taylor

Joanne Cole

Rachel Hext

Sam Rowlands

Mark Forshaw

Lis Hammond

Judith Eberhardt

Angela Marsden

Rachel Batchelor

Ben Gibson

Mia Campbell

Any adult with long covid can use this tool but you should always follow the advice from your health care professional and seek condition-specific advice from sources relevant to your condition. We do not recommend this tool for use by people under the age of 18 years old.

MYLIFE TOOL

Developed by



NEURO KEY

An Alliance supporting people
with neurological conditions



Meaning & Purpose

Living with
Long-Term Conditions



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