

What does self-management mean to you? And how do you want to be supported?

We (National Voices) are gathering the opinions and experiences people with long-term health conditions.

We know that people with long-term conditions have to spend a lot of time and effort managing the impact that those conditions have on their lives. We also know that being supported well to do this can be life changing.

You can help us create a powerful new statement about the importance of self-management and self-care, and how professionals and services should support you to manage your condition on a daily basis.

Here you can take a look at the statements that we've come up so far with people who are very experienced at managing their health conditions.

Throughout this draft document we've asked questions and left space for you to add your thoughts: What do you think of the statements? What would you like to add?

There's no obligation to write something in every box - the spaces are just there for when you have something to add. It doesn't matter if you have full statements to contribute, or a note or idea to jot down - any contribution will be very helpful!

Please share this opportunity with others - the more voices and perspectives we can include, the better!

Complete this form, or write your feedback in an email, and send it to responses@nationalvoices.org.uk by 31 May.

Email Don on info@nationalvoices.org.uk if you have any questions.

Life changing

Self-management has given me my life back.

Self-management has put me back in control, rather than relying completely on health-care professionals.

Self-management helps you create a new belief in what you can do for yourself.

I learned there was something outside my condition. My life wasn't my condition.

The condition is not me.

We don't want the condition to be in control.

I was going down the well to the bottom. Self-management helped me to get back out.

I could have died back then. This is my second life.

I haven't got my life back; but I like my new life.

I am thinking more positively, and being me again.

I was planning a trip to India but I ended up in Bognor. So value where you are now, don't spend all your time wishing you were in India.

My life would have been something different – but the life I have now, the knowledge I have gained, the new things I can do, I would not have had without the illness.

Acceptance; realignment; adaptation.

No to denial. No to being a 'suffering victim'.

Your condition is something you can learn to live with, rather than suffer from.

You can resist the social pressures that tell us what to be and what we can't do. You stop apologising for what you can't do any more.

Do you have anything to add to these statements? Are there any statements you disagree with? Click in the box to answer:

What is self-management?

Self-management means the whole of me is involved. It includes:

- **Self-care:** Treating yourself well and taking care of yourself and needs.
- **Self-consideration:** People tend to put others' needs and wants first, but they should consider themselves as well.
- **Self-nurture:** A little more than self-care. This is about finding new ways of doing tasks and perhaps even engaging in different hobbies.
- **Self-attention:** Being attentive to your own needs.
- **Self-cooperation:** Getting all your parts working together. E.g. A person can be a mother, daughter, sister, and all these parts need to work together so that everything runs smoothly. In the same way, a person has different needs, wants, expectations, beliefs and these all need to work together so that the person is a whole working being.

Everybody with a long term condition self-manages (whether they are conscious of it or not).

It is not just about managing the illness. It is about managing your life with the condition.

Self-management is something you can learn.

With self-management you can take steps to control your condition rather than let it control you.

Self-management means the steps we take to help ourselves manage our lives, including our symptoms.

Self-management is actively managing your life with the challenges that go with your condition.

I can't 'manage my illness' – it does what it will within my body. But I can manage the impact on my life.

The emotional and the social dimensions are far bigger than the medical one.

Self-management is not one thing. It's not one size fits all. It's different for everybody, and everybody gets something different from it.

Self-management is about solution finding.

Self-management is changing the focus from 'I can't, I can't' to 'I can, I can'.

You can think around a problem, without being disabled by it.

You don't stop doing things because you are afraid.

You begin to believe you can get there. You build experience of problem solving, and that helps when you are confronted with something new.

You gain the confidence to challenge handed-down solutions. You can say, 'That's not right for me'.

Do you have anything to add to these statements? Are there any statements you disagree with?

Education

Education is a key intervention, but it's not just about 'education' or a one-off course.

What's important is an 'intervention' that gives people time and space to reflect on what's really going on.

The intervention kick starts us. We are still using the tools and techniques many years later.

The education shouldn't be just handing over information. You get your learning from the group. The knowledge is in the group. It's as much about peer support

You get space to talk and social interaction with people who understand you

The group can provide social support, a shared bond, and peer support over time

The group helps you to see where you are and to bring yourself back up

Self management is not about a course. It's the building of confidence and efficacy

It takes time to build these skills and behaviours.

Self management is about finding out what techniques work for you.

You learn to action plan, to set yourself small, achievable goals

Setting small goals is your bounce-back from low periods. It also helps mark your progress

Learning to set small realistic goals that you can achieve and succeed in enables you to become more confident in setting bigger goals.

Do you have anything to add to these statements? Are there any statements you disagree with?

Confidence is all

I have the confidence to know what I need to do, when to ask for help, and who to ask.

I try to problem solve first.

The more you do it, the more it works, and the more confident you become.

It's like driving – it becomes an unconscious way of doing things.

Confidence is learning to say no if things don't feel right for you.

Whatever your condition, it's up to you to decide what is right for you.

Building confidence is about being determined to take control and responsibility. It can be hard work. Small steps approaches help you get to where you need to be.

Self-management reduces your anxiety, stress and fear about living with the condition

It is a ladder out of the pit.

It works!

The evidence is standing in front of you!

I wouldn't be here if it didn't work

People who have been supported to self manage feel much more in control.

Our evidence needs to matter. We need to judge by patient drivers, not by economic drivers.

The change for me was: I started looking after myself, I stopped having regular hospital procedures, I began using services more appropriately.

14 years on I still use the tools and techniques I learned.

Do you have anything to add to these statements? Are there any statements you disagree with?

Moving beyond diagnosis

At the point of diagnosis, you only see the illness. It's at the centre of your mind all the time.

You feel ill, you are ill, your expectation is that others should care for you.

The beliefs of others also affect you – their beliefs about what you should and shouldn't be doing, and about what you can do.

Belief is a very powerful thing for either enabling or disabling you. It gives or takes away choice.

It's our body and our condition so it should be our choice as to how we manage it.

Self management is about changing your belief and your behaviour: creating a new belief in your own understanding; developing self-efficacy and belief in yourself.

At diagnosis, the medical dimension is bigger than the others. Self management means learning to work to reduce that.

To begin with, managing the medical effects seems really difficult. As we become better at self management, gaining knowledge, skills and confidence, the medical aspects become easier to manage.

Self-management is the Third Way. You can either be:

- in denial that you have a diagnosis, ignoring it, pretending it's not there – then the condition wins because it may get worse;
- a victim, defined by your condition – again, the condition wins;

OR

- learn the knowledge and skills; develop your confidence; be in charge of your life with the health condition then, there is no winner or loser! It's not a battle.

Do you have anything to add to these statements? Are there any statements you disagree with?

Social support

What do you want to be available as social support, in the community? Why is it important and what can it achieve?

Benefits for carers/family members

As you become more skilled and confident to manage, how does this impact on people close to you?

Partnership with health professionals

I expect to be an equal partner in my care.

Do health professionals feel uncomfortable in not giving all the answers? It seems their fall-back is to become the 'expert'.

As an active self manager, I am well despite the NHS.

The NHS tends to treat us as passive recipients. It doesn't usually enable us to be active self-managers. It's often paternalistic.

For example, it's only a few areas that give you access to all your medical records and results. When we do have that, we can see our results without taking up GP time, and make our own judgements about what's important.

We can't be cured. So stop trying to cure us. We want to live well with what we've got.

I want to be offered a range of solutions and see which is right for me.

Professionals often don't do the 'solution-finding' with us. They seem to want to give us the solutions.

Self-management means gaining the confidence to challenge handed-down solutions.

For some of us, the life change comes from learning to say no to the medical interventions.

What I want is to work in partnership with you.

At the moment I have to facilitate the patient-professional partnership and do the donkey work. That means that people without my skills won't get the same quality of partnership.

I would like every interaction with the NHS to support my self-management.

Control should not be on either side. Control should sit in the middle between us.

Give us a role, and we will help you!

Don't feel you have to 'vet' everything you refer us to.

We don't necessarily need health professionals to 'socially prescribe'. If we are supported to gain knowledge we can self-refer.

Trust us to self-refer. It shouldn't always have to be the GP we go back to – that is where we are shoved!

Self-management takes you out of the system. Then times will come when it is right to go back in to ask the questions you need to ask.

Do you have anything to add to these statements? Are there any statements you disagree with?

What are the questions you would like health professionals to ask in every consultation/conversation?

Some ideas:

- What do you most want to talk about?
- What matters most to you at the moment?
- What are you already doing for yourself? How is it working?
- What is a 'good day' for you?
- What further support might help?

What would you like health professionals to ask you in all of your consultations?

Are there any other themes you suggest we include? The current themes are the purple headings - 'life changing', 'what is self-management', etc.

Do you have any other comments about the project or these draft statements?

Finished? Thank you!

Click 'File' then 'Save As' to save your comments, and then email the document to responses@nationalvoices.org.uk.