



# STAND IN THEIR SHOES

## Background

Real people living with long term conditions were asked what they want/need from health and social care professionals to support them to self manage their conditions successfully.

## Overall, have you found that the health/social care professionals you have dealt with have supported self management effectively?

Experience has been mixed. For those with less positive experiences to date, there is a clear sense that things are improving, largely due to a change in professionals' attitudes.

Positive accounts include professionals taking time to truly listen to people who are living with long term conditions, and act on what they hear, crucially recognising the expertise that comes from living with a condition:

**Top Tip:** Communicate effectively. Be willing to engage in a dialogue. Listening is crucial to this.

**"They listen, and they realise it's our life, and we're living with it [Parkinson's] for 24 hours every day."**

Integral to this is showing a real interest in a person's life, beyond their specific condition(s).

Negative experiences included feeling like hospital appointments are rushed and not helpful, largely due to the professional not taking the time to talk to the person they're seeing:

**"I would wait 4 hours for a 5 minute appointment with my consultant and come away feeling that it had been useless."**

Other negative experiences include the fact that, for people who self medicate, hospital environments can be very detrimental to self management if staff are not sensitive to advice from people and carers.

**"All of a sudden, you're out of control and don't know what you're getting when."**

**Top Tip:** Respect the experience a person has of living with their condition(s). You may be able to learn a lot from them.

This can have severe consequences. Good communication, including listening and being open to learning from people who are living with long term conditions, are seen as ways to avoid such situations:

**"It's about respecting a non-professional's experience and taking steps to help."**

**Ideally, what role do you think health/social care professionals should play in the self management of long term conditions? What do you need from them to support you to self management.**

**Top Tip:** Be clear about what self management means – it's not about people coping on their own.

Most importantly, people want health and social care professionals to see them as partners in their own care, and realise that professionals may not always know better.

**"GPs may see very few people with a particular condition, and when they do it's maybe for only a few minutes each month. Therefore, they need to be open to learning from the people who have more constant and direct experience of the condition."**

Being supportive, encouraging, and open to conversation is also important:

**"They should support us by listening to what we're doing and – if we're doing it well – encourage us to continue as we are doing. If we're having difficulties, discuss our options and advice, but listen to our views too."**

There is also a feeling that to support self management, professionals need to give more practical advice, rather than only theoretical, "medical" information. Crucial to this is truly understanding the lives of people living with long term conditions, which includes seeing each person as an individual:

**Top Tip:** Take a general and holistic interest in people's whole lives; not just their condition(s). Get to know them, and make broader suggestions for things which might help with their conditions.

**Top Tip:** Advise – be willing to give information but be careful how this is delivered – be supportive and encouraging rather than critical or negative.

**"We just need a bit more understanding. It's not one size fits all; they need to take the time to look at what works and gets results for each individual."**

The importance of the manner in which professionals give advice also came through strongly – people are looking for supportive advice, rather than critical instruction.

**"Sometimes they can put you down a bit for what you're trying to do. It would be good if they could support you more positively, even if they're advising you on other ways to manage your condition, so that you feel you're capable and don't lose your confidence."**

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