

improving care for people with
long term conditions

information sheet 5

what motivates people to self care



an 'at a glance' guide for healthcare professionals

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About this information sheet

This information sheet is designed to give a brief overview of what motivates people to self care. It is intended to be an aid to reflective practice – to help healthcare professionals approach a self care discussion from the individual's perspective.

Who should read it?

Anyone involved in delivery of healthcare to people with long term conditions, including doctors, nurses, allied health professionals, those delivering personal health budgets and health trainers.

What is self care?

Self care is an integral part of daily life and is all about individuals taking responsibility for their own health and well-being. This includes the actions people take for themselves every day in order to stay fit and maintain good physical and mental health, meet their social and psychological needs, prevent illness or accidents, and care more effectively for minor ailments and long term conditions.

A survey in 2009 showed that 90% of individuals with long term conditions feel comfortable taking responsibility for their own health.

(Source: Ipsos/Mori April 2009)

Individuals are often not clear what we mean by the term "self care". It is important to show the connection between simple things such as brushing teeth and eating a healthy diet, which everyone needs to do, through to doing specific

exercises, pacing everyday activities (including work), taking regular medication (if necessary) and the more involved aspects of self care that are needed to manage long term conditions effectively. It is important to help individuals understand that self care is taking action – just like brushing their own teeth – and they have an important part to play in it.

How does self care differ from self management?

The term "self management" is related specifically to living with a long term condition and has been defined as "the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a long term disorder" (source: *Promoting Optimal Self Care: Consultation techniques that improve quality of life for patients and clinicians*, December 2005).

Individuals with long term conditions have no choice but to live with their condition as best they can. They need to learn to self care as well as manage their condition on a daily basis.



What do people understand about what they can do for themselves?

Many people do not realise they can have an active role in managing their own health and may be surprised to be asked about what they can do for themselves or what their goals are. Healthcare professionals may already experience different challenges in engaging individuals in their care. Where one individual can move to action very quickly, others may need more intense help and support. For example, they may need coaching, motivating or access to other specific techniques such as cognitive behavioural therapy (CBT) before they are "ready" to take a more active role in their health and care.

It is important to understand an individual's motivation to self care. For example, do they want to be more active, return to paid employment, reduce levels of pain, or maybe have fewer admissions to hospital? Often individuals articulate this with statements such as, "I don't want to feel this way". It is important to work with them to achieve the treatment outcomes and longer term goals that they want, at a pace they want, with the support they want.

What is the individual's understanding of their condition?

Many individuals never receive a simple but comprehensive explanation of their condition, so they do not understand what it is or its likely impact on their lives. Therefore a simple explanation is very important.

Individuals learn in many ways but it is through a combination of reading, watching and demonstration that people understand something new. The objective for healthcare professionals is discovering what will best help the individual to understand their condition and in which format.

So, as part of discussing their condition, ask how individuals would like information on their condition. This can be written, spoken, pictorial, having someone take notes or even a mixture.

What do they think caused their condition?

It is important to understand an individual's thoughts and beliefs about why they have their condition, as these beliefs may be a barrier to self care. For example, some individuals may believe that it is "fate" or "God's will" or some kind of punishment for what they have done. They may simply think, "Why has this happened to me?" There is usually no answer to that question and there may be no clear-cut cause.

Individuals may struggle with thoughts and emotions about what they could have done differently to prevent their condition; for example, they might feel that they are responsible for a respiratory condition through smoking or for diabetes through having an unhealthy lifestyle. Equally, if they feel that their condition was caused by someone else's negligence (such as poor working conditions), they may be troubled by thoughts and feelings about blaming a third party.

Negative thoughts about an individual's own actions or ideas such as "blame" are not helpful and are likely to be a barrier to successful self care. Talking through these issues and helping individuals to obtain a more balanced view of the causes can help them to feel more confident about taking steps to manage the condition more effectively themselves.

Family, friends and work colleagues are often an important influence on an individual's thoughts and beliefs and often provide health advice, but this information can be inaccurate and misleading as it is based on someone else's experience. It may be necessary to talk with the individual and their partner or other family members together to help them understand the condition, its symptoms and how best to support them.

For example, encouraging someone with back pain or chronic fatigue to rest all the time is not helpful and family/friends may be unwittingly contributing to the problem by taking over tasks that are part of the individual's role in the family. However, engaging the family in helping them to be active but encouraging them to pace their daily activities more effectively can be helpful.

What do they think is going to happen?

Individuals may fear the worst and feel that their health condition is not something they can manage and that their health will inevitably deteriorate. They may have thoughts like "If I am like this now, what am I going to be like in 20 years' time?" or "I had better stop or cut down on all the things I do in case I make my health worse".

If people have an unduly negative view of their condition, they are unlikely to feel that any effort they make to self care is going to help.

For example, people with angina may fear exerting themselves, thinking it may cause another heart attack. However, medically supervised, light exercise is often recommended to help recovery.

Confidence is key to effective self care; however, many individuals lack confidence. It is important to reinforce the message that their life is not over because they have a long term condition, but it has just taken a different and unexpected turn.

When is the individual "ready" to self care? How can health professionals support them?

As mentioned before, individuals with long term conditions have no choice but to live with their condition as best they can. The real choice comes when they acknowledge their condition and begin their journey of developing the knowledge, skills and confidence that can help optimise their quality of life and (perhaps) slow the trajectory of their condition.

There are two key issues to think about here:

- **Acknowledgement** – Making sure the individual and their family understand and accept that they have a long term condition which has no cure and the part they need to play in its management will help to ensure that the individual is in the correct state of mind before they begin their self management journey. Acknowledgement is not about giving up but is a gradual process of recognising and understanding that they have a health condition which requires them to take more control and to develop the skills and confidence to self manage it. This can be hard for some individuals, who feel uncomfortable with the idea of having to manage their health themselves and feel that it is the role of healthcare professionals to do this for them.
- **Supporting self care** – It is important that healthcare professionals act appropriately to support self care and do not just either discharge the individual ("There's nothing more we can do for you") or disempower them ("I think you should have another test" or "I think you should go and see this specialist").

Although the individual has to be ready to engage in self care, the healthcare professional has to be ready to “let go” and work in more of a partnership with them – teamwork. This means handing a large amount of power and control over to the individual and their family – when they are ready to take it on. Getting the timing right is difficult and is often a gradual process that needs to be done over time.

It is important to provide encouragement for individuals to self care. Be clear from the beginning about what help and support will be provided, but also make people aware they will have a large part to play in the process as well.

Information sheet 6: Goal setting and action planning as part of personalised care planning builds on the approach set out in this document.

Further information for healthcare professionals

Health needs assessment tool

A health needs assessment (HNA) tool developed by NHS Kirklees helps healthcare professionals to identify the needs of the individual and target resources more effectively, offering more personalised support to individuals with long term conditions. For more information on the HNA tool in Kirklees, please visit www.kirklees.nhs.uk/your-health/helping-yourself-to-better-health/self-care-toolkit/overview-of-self-care-options/health-needs-assessment/

Well-being Star™

The Well-being Star™ for long term conditions is another free tool that can support healthcare professionals in their care planning discussions. The tool works by encouraging the person to consider a range of factors that impact on their quality of life. These are not restricted to health, but cover a broader range of issues including lifestyle, looking after themselves, managing symptoms, work/volunteering/other activities, money, where they live, family/friends and feeling positive.

The PDF version of the tool is free to download and use within your organisation. To register please go to www.outcomesstar.org.uk

Personalised Care Planning and Information Prescription e-learning toolkits*

NHS Employers has produced two e-learning packages to help develop the skills and knowledge needed to produce personalised care plans and Information Prescriptions.

www.nhsemployers.org/PlanningYourWorkforce/LongTermConditions/Pages/LongTermConditions.aspx

Supporting Self Care e-learning toolkit*

This is designed for healthcare professionals supporting people with long term conditions.

www.e-lfh.org.uk/projects/supportingselfcare/index.html

End of Life Care for All e-learning toolkit*

Enhances the training and education of all those involved in delivering end of life care.

www.e-lfh.org.uk/projects/e-elca/index.html

*Please note you will need to register with the site provider to access these toolkits



More information on personal health budgets can be found at:

www.personalhealthbudgets.dh.gov.uk

Publications and other resources on long term conditions management are available at:

www.dh.gov.uk/longtermconditions

The series of information sheets is available to download at www.dh.gov.uk/longtermconditions and covers the following topics:

Information sheet 1: Personalised care planning

Information sheet 2: Personalised care planning diagram

Information sheet 3: Care coordination

Information sheet 4: Assessment of need and managing risk

Information sheet 5: What motivates people to self care

Information sheet 6: Goal setting and action planning as part of personalised care planning

Information sheet 7: How information supports personalised care planning and self care

Information sheet 8: End of life care and personalised care planning

Look out for further information sheets covering other relevant topics.

Your feedback is extremely important to us. Please send your comments/suggestions for this information sheet, or good examples of personalised care planning and supported self-care within your area, to longtermconditions@dh.gsi.gov.uk