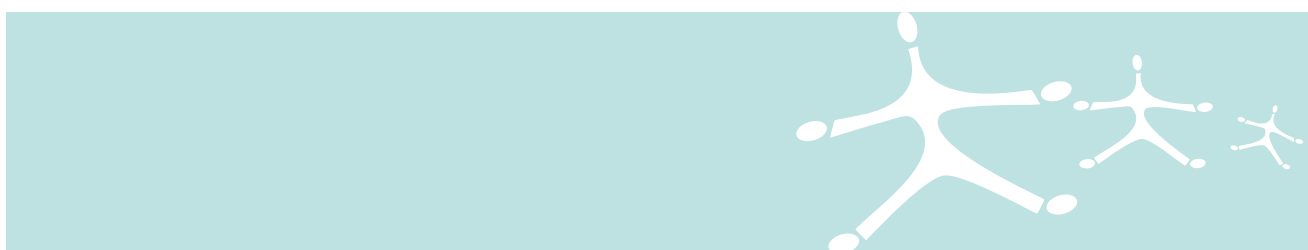improving care for people with
long term conditions

information sheet 7

how information supports personalised care planning and self care

an 'at a glance' guide for healthcare professionals

how information supports personalised care planning and self care

improving care for people with long term conditions

About this information sheet

This information sheet describes the role of high quality, timely and relevant information in enabling a good care planning discussion and supporting self care.

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.

How does information support personalised care planning?

Information supports care planning in two different ways:

(i) Providing individuals with information

Discussing information needs is a crucial element of personalised care planning. The information provided to the individual and what has been agreed can be recorded in the care plan. This may include information:

- about specific conditions;
- about personal health budgets;
- on setting goals and action plans;
- on dealing with setbacks;
- on support groups – both national and local;
- in the form of signposting to information on other services such as housing and benefits;
- about self management courses such as the Expert Patients Programme.

People have different information needs depending on what stage they are at in their lives and their conditions; information needs are therefore ongoing and should be tailored to an individual's needs.

It is good practice to consider what format is most helpful for the individual. For instance, some individuals may want an electronic copy, while others may not.

(ii) Sharing information with other agencies

This is an essential element of personalised care planning. Information needs to be shared across agencies involved in an individual's care to support:

- cross-agency and multi-disciplinary working;
- individuals in receiving better coordinated care;
- personalised care planning and commissioning;
- appropriate cross-agency and multi-disciplinary access to care plans and care outcomes;
- less duplication of work;
- service evaluation and assurance that person centred care planning is happening;
- research, financial management and other secondary purposes.

2

It is important to understand and document what information will be shared with each agency. It is equally important to be able to explain this to individuals so that they understand what information is being shared about their care.

There are **rules and protocols governing information sharing**. These requirements and constraints will vary according to the nature of the information and the circumstances that apply. For more information on the NHS Code of Practice on Confidentiality 2003, please visit: **www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf**

Why is information important to support self care?

While information on its own is not enough to change an individual's behaviour, quality of life or clinical outcomes, there is good evidence to suggest that a better understanding of a long term condition can positively affect an individual's understanding of their symptoms and long term health.

Individuals will differ in their information needs according to where they are on their "healthcare journey" and they may differ in their preferred method of receiving that information.

Ideally, an individual's preferred method of being informed needs to be established as early as possible in any discussions.

When providing information for individuals to self care, it is important to understand how they will use it. It needs to be in a format they will understand – it could be written, verbal and pictorial, recorded or even a mixture.

What information can support self care choices?

There are five key areas where information can help people to make informed choices about the kind of support they wish to access from the resources available. This includes:

• **healthy lifestyle support:** to help improve diet and exercise regimes;

• **information:** advice about an individual's condition and its treatment;

• **skills training:** to boost confidence and learn coping skills;

• **tools and equipment:** to make life easier at home;

• **support networks:** to help find people to share experiences with.

This information is likely to be readily available from a range of sources in a variety of formats (see below).

Keep the information simple – what may seem simple to understand may be difficult for the individual, especially if they have low health literacy.

What sources of information are available?

People can find information about general well-being issues and specific conditions from many different sources. Local libraries, adult education facilities, workshops and courses may have books and leaflets, CDs and DVDs available.

Community and voluntary groups also play an important role in encouraging people to learn more about their condition and what might help them.

Self care support networks and local and national charities offer a range of information. The internet can also be a good information source; however, individuals need to know which sites can be trusted (see "What is the Information Standard? How does it support you?" below). NHS Choices (**www.nhs.uk**) contains quality assured information and links to other helpful services. It also provides Information Prescriptions for a number of long term conditions.

How do Information Prescriptions support individuals to make informed choices?

Information Prescriptions (IPs) aim to provide individuals who have long term conditions and their carers with timely, relevant and reliable information, to help them feel in control and empowered to make decisions about their care. They not only provide information on health needs but also offer information on wider aspects of health and well-being, including access to benefits and social care services. This fits with a more personalised and holistic approach to care delivery – supporting optimal health and well-being and increased choice. For more information about IPs, please visit: **www.informationprescription.info/**

How does *Your Guide to Local Health Services* support people to make the right choices?

Your Guide is produced by every primary care trust (PCT) and provides people and local communities with information to help them make the best use of their local health service.

Your Guide provides:

• **information** about the range and quality of local services to assist individuals in making the right choices for them and in using services more appropriately;

• **accountability** back to those who use and pay for local services by telling them how the money has been spent and how health services will change in response to user feedback;

• a **signpost** to more detailed information when individuals want it.

By having access to information on local services, individuals will have a better understanding of how to navigate health services, what choices are available to them and how to contact their local PCT.

Your Guide complements key national services and information sources such as NHS Choices and NHS Direct. Individuals with long term conditions can obtain information and services to support self care at **www.nhs.uk/yourhealth**

> **Review the information you already provide to individuals and carers and decide what may be needed in the future: individuals need access to good quality and comprehensive information they can understand and trust, as and when they need it.**

What is the Information Standard? How does it support you?

The Information Standard, previously referred to as the Information Accreditation Scheme, is a new certification scheme that can help individuals to identify reliable information sources. Through the scheme, health and social care information producers will be able to place a quality mark on their information materials to reassure individuals that the health and social care information comes from a reliable source.

For more information and a full list of scheme members, please visit: **www.theinformationstandard.org**

Further information for healthcare professionals

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/PlanningYour Workforce/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

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

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