

Agreeing Individual Care with People who have Long Term Conditions



Responding actively to the needs of people with mental health, cancer and long term conditions through the use of individual care plans

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1. Independence, not dependence

Promoting independence, not dependence and prudent healthcare are key and integral principles of agreeing individual care with people who have mental health, cancer and other long term conditions. Agreeing individual goals, action and care is well established good professional practice. We have long reflected this in our policies, recognising the importance of motivating people to take responsibility for their health and wellbeing and to agree their needs with the professional through a care plan.

The way the relationship and dialogue between the professional and the individual is conducted is critical. We must avoid '*doing to*' rather than '*doing with*'. This Framework offers a guide to what a care plan is and the core characteristics of agreeing care. It highlights some of the benefits for both individuals and for professionals. Although it is aimed primarily at professionals, it is written to be accessible by anyone. To complement this Framework, we have asked the Long Term Conditions Alliance Cymru to develop a short public facing version.

The Welsh Government will also be publishing a Framework for Self Care. This will set out a range of strategic actions to promote this key principle of effective management of long term conditions.

For people aged 65 and over who have care and support needs, including those with long term health conditions, we published new statutory guidance on 2 December 2013. This guidance applies to the NHS and local authorities and sets out how to assess, plan and review care with individuals. The guidance entitled Integrated Assessment, Planning and Review Arrangements for Older People is available through the link below:
<http://wales.gov.uk/topics/health/publications/socialcare/guidance1/assessment1/?skip=1&lang=en>

2. What is an individual care plan?

At the end of any discussion, the professional and the individual summarise what is agreed, in what is called an 'individual care plan'. As this is proportionate to the needs and preferences of the individual, this can take a variety of forms. For example, a 25 year old person with asthma may just want a simple verbal understanding and agreement. Someone else may decide they want some brief notes to act as a prompt, others may ask for written material such as leaflets or guidance from the internet. For people with more complex needs, such as an older, frail person, they may want a more detailed document.

An 'individual care plan' – perhaps better described as 'an individual care agreement':

- is a summary record of the outcome of the jointly agreed and regularly reviewed needs, preferences, goals, informal and formal care and support, action by the individual and action by the professional;
- if captured as a written document, is available on shared IT systems to those professionals involved and is integrated with other care plans where appropriate;
- promotes self reliance and management by identifying prompts for self care, acts as a repository for and/or signposts the individual to sources of relevant information, advice and support, such as that provided by the third sector;
- acts as a common point of reference for the professionals involved, avoiding the need for the individual to repeat information, and supports co-ordinated and integrated care across professionals and organisations;
- lists all people involved in the ongoing care and support of the individual, including carers, family, friends, neighbours and the local community as well as professionals, their role, the actions they are responsible for and how they can be contacted;
- includes information on what to do in an emergency.

The care plan is not bureaucratic or unnecessarily time intensive. It is always proportionate to need, and provides a range of benefits to both the individual and professionals.

Good practice is for the individual to keep a copy, hard or electronic, of the plan as a prompt and a point of reference for discussions with carers and family and may contain contact details for the professionals involved. If a verbal agreement has been reached then a brief note that the discussion has been held and agreement reached is recorded by the professional.

The Hand Held Maternity Record is a good example of this. All pregnant women hold their record and take it with them to consultations with midwives, obstetricians and GPs. There are very few problems associated with this and the records are rarely lost.

An individual care plan is not a substitute for an individual person's formal medical record or other legal record requirements.

3. What are the core characteristics?

The more detailed set of principles and Welsh Government guidance, Integrated Assessment, Planning and Review for Older People can and should be applied to people aged less than 65. This section highlights three simple but core characteristics which underpin all good practice and are designed to promote independence, not dependence.

i. Holistic Care and Support – ‘Seeing the individual as a whole, taking into account all aspects of their life, not just treatment’

Discussions between the individual and the professional take a holistic view of the person’s health and wellbeing, including emotional and psychological issues, education, employment, housing and transport, but are proportionate and responsive to that person’s needs and preferences.

The professional begins with the question *“what can we do together to address the difficulties and the problems that you are experiencing?”* This is about not doing things that do not do any good and avoiding things that do harm.

The *‘ask three questions’* initiative, based on **research** from Cardiff University and the Health Foundation, encourages people with chronic conditions to the following key questions when they are asked to make a decision about their care.

- *What are my options?*
- *What are the pros and cons of each option for me?*
- *How do I get support to help me make a decision that is right for me?*

Discussions help identify and deal with concerns; promote discussion of options; motivate identifying goals and actions by the individual; enable shared decision making, involve others as required and; consider all relevant areas of someone’s life

This may include informal support from family, friends, neighbours and the local community or more formal referrals for support from the NHS, social services, housing, transport and the third and independent sectors. Discussions provide an opportunity for shared decision making based upon the individual person’s need and not the needs of the system caring for that person.

Where appropriate, discussions can focus on referring the individual to local services, often provided by the third sector, which offer practical, non clinical advice and support. In practice, this means that GPs, nurses or other professionals work with the individual to identify non-medical opportunities or interventions that help them adopt healthier lifestyles or improve wider social aspects of their lives.

The resulting services people might opt for could include everything from debt counselling, support groups and walking clubs, to community cooking classes and one-to-one

coaching. These 'social prescriptions' can be seen as a natural extension to 'information prescriptions' – which are tailored information given to individuals to help them make informed choices about their care and to access a wider range of services, such as social care, housing and leisure services.

The discussion process recognises when more specialist input is required. Individuals with disability, co-morbidity or complex medicines management regimes have discussions on the relative benefits of medications versus risks to health and quality of life, supported by decision making tools.

The conversation concludes, through the individual care plan, with an understanding and agreement between the individual and the professionals involved on the individual's goals and actions for them, and what informal and formal care and support is available.

ii. Coordinated and Integrated Care and Support – *'Everyone involved working and communicating together'*

The individual care plan supports joint working across professionals and organisations. It is used as a common reference point by the individual and all professionals involved for all discussions with the individual regardless of what element of the care pathway they are on. It is important that the care plan is jointly owned by the individual and all the professionals involved.

Where several professionals are involved in discussions with the individual, the care and support available is co-ordinated and integrated across primary, community and secondary care and between the different organisations of the NHS, local government and the third and independent sectors. Care and support is experienced as seamless by the individual and in most cases where the care is more complex, it is clear and agreed which professional takes overall responsibility for co-ordinating the formal care and support agreed.

iii. Individuals Involved and Engaged – *'Professionals working in partnership with individuals'*

The principle of shared decision-making in the context of a clinical consultation is that it:

- informs the individual about their condition, about the care and support options available, and about the benefits and risks of each;
- supports the individual to articulate their understanding of their condition and of what they hope their agreed care and support, including self management, will achieve;
- ensures the individual and professional arrive at a decision based on mutual understanding of this information, record and implement the decision reached.

Involving an individual as an equal partner in assessing and agreeing their own needs, preferences, goals and actions supports a system built on personal independence, not dependence.

The process anticipates problems and as well as agreeing action to prevent problems, the care plan/agreement may usefully include agreed contingency plans ('safety netting') for emergencies and exacerbations of problems. This includes self management as well as clear trigger points where professional advice should be sought.

Although the focus is on the individual person, there may be others (parent or carer) directly involved in decision making for children or vulnerable adults. Achieving meaningful participation in the process of individual care may raise consent and confidentiality issues, which become an explicit part of the shared decision making and record keeping.

“ Care planning is about making more effective the dialogue between the patient and clinician, that is so vital to the care we provide every day and changing the doctor-patient relationship into a doctor-patient partnership. ”

– Royal College of General Practice
(RCGP) Guidance on Care Planning (2011)

Individuals with complex problems, their family and carers greatly value a single point of contact with a professional who is responsible for overseeing and co-ordinating the delivery of their agreed formal care and support. Professionals communicate effectively with colleagues within and outside their own teams. All professionals make sure that the individual and other colleagues understand individual roles and responsibilities and in particular, who is responsible for each aspect of informal and formal care and support. This is of particular importance when care requirements are complex.

In these cases, the support of a care co-ordinator or key worker, such as a specialist nurse, may be appropriate. It is important that this key contact is agreed with the individual, their family and carers and is communicated to everyone involved in providing care and support and is recorded within the care plan.

4. Motivating professionals and people to agree individual care plans

Agreeing individual care results in that person feeling well informed and motivated in managing their health and wellbeing. This, in turn, reduces the demand on planned care in terms of GP appointments and referrals to hospital, and on unscheduled care such as GP out of hours and Accident and Emergency services.

Some of the expected benefits are set out at Annex A.

To complement this guide, the Welsh Government has asked the Long Term Conditions Alliance Cymru, which is made up of a number of national charities which offer information, advice and support, to produce a short public facing guide for people with long term conditions. This will promote the message of 'independence, not dependence' and explain the nature of discussions with professionals to agree goals and actions.

The NHS Wales Informatics Service is leading an all Wales programme of work to develop information systems that will support primary and community care.

5. How can we measure if people are better off as a result?

We already, and will continue to, monitor and measure the ongoing reduction in the number of people with the main 8 long term conditions who are admitted to hospital or readmitted within a year as an emergency and lengths of stay in hospital when admitted. These reductions tell us people are increasingly managing their condition effectively and that there are more options available in primary and community care when care from the NHS, local government and the third and independent sector is needed.

From 2014, we will use the annual National Survey to ask people with long term conditions if they feel well informed and motivated in managing their health and wellbeing through their discussions with professionals and their individual care plan.

“ Every patient/client is a unique individual with their own set of needs and desires. Each one has the right to have their healthcare needs met and their wishes respected. They have the right to discuss their care on a regular basis with the healthcare professional responsible for their care. ”

– Designed to Realise our Potential
(Welsh Government 2008)

Annex A

Benefits of Individual Care

Benefits for the Individual include:	Benefits for Professionals include:
<ul style="list-style-type: none"> • Control over personal goals. • An opportunity to express personal preferences and to understand and agree options of available care and support. • Able to access professional care from home through increased use of phone, email, Skype, remote monitoring of blood pressure, glucose levels. • Knows where to go for information, advice and support. • Knows when and how to take medication. • Less chance of having to repeat the same personal information to several different professionals. • Less likely to need unplanned care, such as an emergency hospital admission. • More likely to return home promptly and appropriately from hospital. • A named lead professional (sometimes referred to as key worker/care co-ordinator) where this is agreed and how to contact them. • Less chance of gaps in care. • Understanding of the role of each person involved in their care, who will do what and by when. • Confidence and satisfaction with formal care and support. 	<ul style="list-style-type: none"> • Partnership with the individual and engagement in their own health and wellbeing. • Opportunities to provide effective individual care on a 24/7 basis at home and in the community, leading to reduced visits to GPs, outpatient clinics, inappropriate emergency hospital admissions and prompt hospital discharge. Access to relevant information about the individual. • Agreement over a named lead professional (sometimes referred to as key worker/care co-ordinator). • Agreement on action by whom and by when to prevent problems and early intervention. • Less duplication and ability to identify gaps in care. • Continuity of care and integration between professionals across primary, community and secondary care, between the NHS and local government and with the third and independent sectors. • Improved communication with the individual and with other professionals. • Confidence in signposting to reliable sources of information, advice and support. • Appropriate use of medication. • Reduced clinical errors.