My Health in My Hands

Public & Patient Guide to Individual Care Plans for People with Long Term Conditions
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Public & Patient Guide to Individual Care Plans for People with Long Term Conditions

People with long term conditions need long term support to minimise the impact of their conditions and maximise their quality of life. They need timely and effective medical treatments, but they also need information and support to manage their conditions on an ongoing and daily basis. They need to feel engaged with their own care, to feel responsible for their own health and able to make decisions for themselves. We believe a patient centred care plan is an important tool in the overall treatment of people living with a long term condition.

– Long Term Conditions Alliance Cymru
1. What is an individual care plan?

The Welsh Government has made a commitment that if you have a long term health condition you will have a care plan if you want one.

A care plan is an agreement between you and your health/care professionals about what is needed to help you manage your life day to day. It should set out clearly the care you need, and who will provide it, and covering other sorts of support you may also want. An example can be a maternity record.

It can be a written document which you keep or something which is agreed verbally with you and recorded in your patient notes. Most importantly it is there to help YOU. It shows how you are one of a team working for your benefit:

"Care Planning is about making more effective the dialogue between the patient and GP that is so vital to the care we provide every day and changing the doctor-patient relationship into a doctor-patient partnership."

– Dr Clare Gerada, Royal College of General Practitioners

A care plan is something that, if you wish, can be shared more widely with others involved in your care such as carers, family members and support organisations.
2. How will a care plan help me?

Care planning puts you at the centre of discussions about your care. It identifies how you will get the support you need to manage your condition and achieve a better quality of life, in line with your own personal needs and aspirations. A care plan can help you to:

- fully understand your condition and what it means for you;
- understand and deal with the impact of your treatment on your life;
- play a role in managing your condition, with confidence and success;
- stay independent and in control;
- achieve your personal goals, that is the things you would like to be able to do such as getting out more, getting back to work;
- identify where you can get information, advice and support;
- avoid having to repeat personal information to several different professionals;
- make sure all the care you receive works for you.
Case Study

I’d got more anxious and depressed as my arthritis got worse. Sitting down with my doctor to discuss things other than pills and potions made me realise my depression was actually making my arthritis worse! As part of my care plan we looked at how I could go to a support group. I get out more now and have new friends who have helped me understand my illness better. My confidence is growing to try new things and I’m even going to the gym which I’d never thought possible!

– (Heather, 58 years old)
3. What does it involve?

A care plan looks at not just your medical treatment but at your life as a whole. That may involve practical points such as education, employment, housing, transport, and money matters as well as emotional, psychological and spiritual issues.

You will work with your health professionals to focus on:

- what is important to you;
- the goals you have;
- the actions you can take to stay well such as losing weight, stopping smoking or increasing your physical activity;
- how to get the biggest benefit from your medication;
- organising as one the care and support you need from health services, social services, family, friends and support organisations;
- dealing with anything which may be worrying you, for example how isolated or anxious you may feel.

Case Study

Whenever I go to discuss my care plan I always write down the things I want to talk about and ask – it really helps because you can forget when you get in there. The ones I always ask are:

- What are my options?
- What are the pros and cons of them?
- When can I expect an improvement?
- Where can I get more information?

– Nigel, 32 years old
As your life and health change over time, your care plan must change too, and it should be reviewed regularly to keep it updated. Care and treatment plans for some people such as those receiving secondary mental health services will be completed on statutory forms and there will be particular requirements for these.
4. Self Care

The whole reason behind the care planning process is to enable you to be an equal partner in assessing and agreeing your own needs, preferences, goals and actions and to enable you to look after yourself in a healthy way and in particular to enable you to self care.

Living a healthy lifestyle is an important part of self care for everyone. Self care doesn’t mean getting less help from your doctor; it involves having the support and knowledge to improve your own health and wellbeing.

“Self Care refers to an approach where individuals together with their family/carers and community take responsibility for their own health and well-being, with professionals playing a supporting and facilitating role rather than one of fixing problems. This includes: supporting and encouraging people to agree their own goals; take action to be fit and healthy, both physically and mentally; taking actions to prevent illness and accidents; using medicines and the NHS in the right way and; managing the impact of long term conditions on daily life.”

– Martyn, 2002

cited in Supporting people with long term conditions to Self Care, Department of Health 2006
5. Where can I get further information?

The Welsh Government have published a guidance document entitled Agreeing Individual Care with People who have Long Term Conditions which provides further information on what a care plan is and the steps which should be taken when agreeing care. It highlights some of the benefits for both individuals and for professionals.

Link to full framework document here.

If you would like specific information on your condition or contact details for support organisations you can find further information at www.nhsdirect.wales.nhs.uk/

The Long Term Conditions Alliance Cymru is an umbrella body of voluntary organisations working with and for people with long term health conditions. Our aim to improve the quality of life for people living with long term conditions in Wales, their families and carers.

Members of the Alliance include:

- Action on Hearing Loss
- Alzheimer’s Society
- Arthritis Care
- Ash Wales
- Asthma UK
- Breast Cancer Care
British Heart Foundation
British Lung Foundation
Carers Trust
Changing Faces
Deafblind UK
Diabetes
Cymru
Epilepsy Action Cymru
Epilepsy Wales
Fibromyalgia Support Group South Wales
Gofal
Kidney Foundation Wales
Macmillan
Motor Neurone Disease Association
MS Society
Pernicious Anaemia
Parkinson’s UK
RNIB
SHINE Charity
Stroke Association
Terrence Higgins Trust
Tenovus
Wales Association of CFS and ME
Welsh Kidney Patients Association