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Living with a long-term condition

A long-term condition cannot be cured but its symptoms and complications can usually be controlled with treatment. Examples are arthritis, asthma, diabetes, epilepsy and high blood pressure. Long-term conditions can have an effect on your role within the family, your job, your accommodation, your education and your finances. However, there are many sources of support you can access, including health and social services, the government and voluntary organisations.

What is a long-term condition?

A long-term condition is an illness that cannot be cured but can usually be controlled with medicines or other treatments. Examples of long-term conditions include arthritis, asthma, diabetes, epilepsy, angina, heart failure, and high blood pressure (hypertension).

Impact of a long-term condition

You may find that having a long-term condition will affect many areas of your life. These may include family relationships, your ability to work, your accommodation, your educational needs and your finances.

You will not have to face your problems alone. Many sources of support are available to you, including your GP, hospital doctors and social and community services.

Accepting support

You may find that your role within your family changes. If you were the 'go to' person everyone else relied on, it may be hard to accept that you are the one who now needs support. At the other extreme, your family/carers may overestimate the amount of help you need, leading to unnecessary loss of independence. The way to combat this is for you and your family/carers to learn as much as possible about your condition. Getting your 'support network' involved in this process will help them recognise when you require help and when your independence should be respected.

Managing your long-term condition

Research suggests that the people who do best are those who take responsibility for managing their own long-term condition in partnership with their doctors. Knowing what treatment options are available will give you the confidence to understand when to manage your own condition ('self-care') and when to ask for help, Managing your own condition is easier when you are involved in decisions about your treatment from the start. You may have to remind health professionals that you have this right and that it is Department of Health policy. Your GP, hospital specialists, voluntary organisations, the internet and the library may all be useful sources of information.

Self management UK (see below) offers self-management courses which provides tools and techniques. These help you to take control of your health and manage your condition better on a daily basis. It may be free, depending on where you live.

Personal health budgets were introduced by the NHS in April 2014. The budget is an amount of money to support your identified health and wellbeing needs. You will need to agree a care plan with your local NHS team so decisions can be taken about how the money is to be spent. The idea of the personal health budget is that if you have a long-term condition you will have greater choice, flexibility and control over the healthcare and support you receive. You may, for example, choose to spend some money on a community nurse and some on support from a voluntary organisation. The money will need to be kept in a bank account used only to purchase healthcare. You may also qualify for a separate budget to purchase social care.

Long-term conditions and employment

When you have a long-term condition, you should keep working if your health permits. This has been shown to bring long-term benefits. It is best to make your employer aware of your condition and have a discussion with them to see whether they could make any changes to meet your needs. It is best to do this on an informal basis but if you meet resistance, legislation such as the Equality Act 2010 may give you a legal right to request such changes.

The changes you require may include:

- Alterations to your workspace.
- Working different hours.
- Working in a way that makes allowances for your condition (for example, having more breaks).
- Equipment that may help you.
- Going back to work on a part-time basis after being off sick.
- Making your job less pressurised.
- Sharing work with others when you are under pressure.

If you have been off sick you should have a discussion with your GP about when it will be appropriate to go back to work. If necessary, the GP can give you a 'fit note' advising of any changes they feel need to be made to your workplace.

You may also be able to get support from your occupational health service at work. If your employer does not have one, you may be able to access a national occupational service.

Long-term conditions and housing

You may find that your long-term condition requires you to make changes to your accommodation. For example, you may need to consider making structural changes, installing a lift or even moving to a single-storey property. You may be able to get a Disabled Facilities Grant to help pay for these changes. Usually, the grant is only available for changes that have been recommended by an occupational health therapist.

Long-term conditions and education

Children with long-term conditions have the same rights of admission to school as other children. You should make the school aware of your child's condition so that the teachers can plan what support they will need and how to protect them from risk. Asthma, diabetes and epilepsy are typical long-term conditions of which the school needs to be made aware. Sometimes, your child may need to attend a school which specialises in providing the equipment and environment that meets their needs.

Issues you may need to discuss with the school include:

- Medicines that may be required during the school day and what side-effects they may cause.
- What emergencies might arise and how to deal with them.
- Any special requirements such as diet.
- Anything that needs to be done before physical activity (eg, have a puff of an asthma inhaler).
- What will happen if your child needs to attend medical appointments on school days.

Remember that schools are not obliged by law to give your child medicines but if staff agree to do so, they should be properly trained.

Long-term conditions and finances

People with long-term conditions may qualify for a whole range of benefits, tax credits, grants, payments and concessions. These may include help with transport costs and parking, help to buy support from a carer, housing benefit and council tax reduction, income support, working tax credit and VAT exemption. You may also be able to claim special sources of finance if your condition is occupation-related or you were a member of the Armed Forces.

Further reading

- Long Term Conditions Compendium of Information, Third Edition; Dept of Health, 2012
- Disability Rights; GOV.UK
- Disabled Facilities Grant; Northern Ireland Housing Executive.
- Financial help if you're disabled; GOV.UK
- Personal Health Budgets; NHS England
- Advice for employees on working with a long-term medical condition; NHS Employers.
- Illness and your child's education; GOV.UK

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