

## Caring and illnesses

### Caring for someone with a condition

As a young carer, you'll probably want as much information as possible about the condition of the person you care for. Don't be afraid to ask questions. Not knowing about a condition and what might happen can be much more worrying than having the information.

It's worth talking to the person who has the illness or disability to find out how it affects them. You could also talk to any doctors, nurses, social workers or other people who help that person.

Online support workers at websites for young carers (such as [youngcarers.net](http://youngcarers.net)) could also provide answers to your questions about caring. You can post messages to other young carers and share your experience with people in similar situations. These websites can help you find out about a young carers service near you.

Below you'll find information on caring for people with:

arthritis,

cancer,

cerebral palsy,

dementia,

multiple sclerosis, and

stroke.

In other pages in this section you'll find information on caring for people with:

blindness or limited sight, deafness or limited hearing,

drug or alcohol misuse,

learning disabilities including autism, Asperger's syndrome and Down's syndrome, and

mental health issues such as anxiety or depression, schizophrenia, obsessive compulsive disorder, self-harm or suicidal behaviour.

If you're looking after a relative who is ill, it's natural to worry about their health problems and to wonder if the same thing will happen to you in the future.

If you're worried about illness:

Talk to the person you care for. They may not talk to you openly about their condition because they may feel it would upset you. Explain your concerns to them and how you feel not knowing about their illness.

Talk to adults you're in contact with through caring, such as doctors or social workers. They'll be able to tell you which illnesses you can catch and which you can't.

Your chance of getting the same illness as a relative depends on the type of condition they have. Many illnesses are caused by factors such as what people eat or drink, how much exercise they do and whether they smoke. These are called environmental factors.

Other conditions are simply down to a person's age. Your body wears out over time and, as you get older, you may not be able to get about as quickly.

However, some illnesses, such as some cancers, are hereditary, which means they can be passed on to you through your genes. Others, such as flu or hepatitis C, are contagious, which means anyone can catch them.

### Protecting yourself

As a young carer, you shouldn't be expected to take on a demanding caring role. However, there are times when it may help to know how to protect yourself from a contagious disease.

If the person you care for has a contagious disease, take extra care not to touch any blood or other bodily fluids. For example, be careful when handling anything, such as bedding, that may have come into contact with bodily fluids. If you have a cut, wear a clean plaster or bandage or gloves to protect yourself.

You shouldn't need to touch needles or syringes that are needed by the person you look after. However, be aware that:

A needle and syringe should only be used once.

Caps should never be put back on needles.

Needles should never be taken off syringes.

Used needles should not be bent or broken.

Used needles should not be put in the bin. They must go in a clearly marked safe container.

Caring for someone with arthritis

Arthritis is a painful problem which affects the joints, such as knees, hips and ankles.

The pain of arthritis can either be sharp and stabbing or a dull ache and can vary from day to day. Some people say the cold and damp can make their arthritis worse.

Ordinary tasks can become difficult. The person is in quite a lot of constant pain so can become very tired and sometimes get upset or angry. The skin around the joint can become swollen, hot to touch and red.

Arthritis can be caused either by the tissues between the bones gradually wearing away causing the bones to rub together (known as osteoarthritis), or by the body's immune system attacking a joint causing swelling and pain (known as rheumatoid arthritis).

Osteoarthritis usually affects people over 50. Repeated movements of the same type, being overweight or a previous injury to the joint can all be causes. Rheumatoid arthritis can affect younger people, more usually women, and researchers think it may be inherited.

People with arthritis can get access to a variety of treatments to help deal with and manage the pain. Painkillers reduce the pain while anti-inflammatories reduce the painful swelling around the joints. Physiotherapy and exercise can help reduce the pain from arthritis and stop the symptoms getting worse.

Sometimes surgery is an option, especially for patients with osteoarthritis in the joints, such as the hip and knee. The joint can be removed and replaced with an artificial one, which helps the patient lead a more pain-free life.

Rheumatologists are doctors with specialist knowledge of arthritis (usually rheumatoid arthritis) and its treatments.

Orthopaedic surgeons have specialist knowledge of working with joints and can advise someone with arthritis (usually osteoarthritis) about surgery available to them.

Occupational therapists will decide if the person with arthritis needs special equipment to help them be independent and return to their homes.

Physiotherapists are trained to help someone learn how to do physical tasks, such as picking things up or walking. They'll help the person with arthritis become more mobile and independent again by giving them lots of exercises to do.

### Caring for someone with cancer

Cancer is caused when normal body cells start to divide and grow uncontrollably. The dividing cells create a lump called a tumour.

'Benign' tumours are harmless and normally only need to be removed if they grow too big or cause pain or problems for other body parts nearby.

'Malignant' tumours can grow into nearby body parts so it can be difficult and sometimes impossible to remove them. The tumour can also spread and grow in different parts of the body. Sometimes a cancer is not a tumour but is found in the bone marrow or lymph nodes.

The terms 'primary' and 'secondary' cancer are used to describe what type of cancer people have. Primary cancer refers to the place where the cancer starts. Sometimes the cancer cells break away from this area and are carried by the blood around the body to form new tumours somewhere else. These new tumours are called secondary cancers.

### Symptoms

The symptoms of cancer vary enormously according to the type of cancer. A lump found in the body is one sign, but some lumps can be non-cancerous. Many people notice a small change in the part of the body where the cancer starts. Others feel unwell, suffer from breathlessness and have unexplained bleeding and weight loss.

Lots of research is going on into what causes cancer. People who smoke, for example, are much more likely to develop cancer. The chance of getting cancer increases as we get older, but not all old people get cancer. Scientists have found that if we keep fit and healthy by eating well, exercising and being a sensible weight, we reduce our chances of getting many cancers.

Some cancers are inherited. This doesn't mean that someone with a parent with breast cancer will automatically develop it themselves. It may just mean their

risks are higher than for someone without a parent with breast cancer. In this situation, doctors would be happy to talk to anybody who's worried about this and to discuss options with them.

Usually a doctor will refer someone to a hospital where they can get specific tests to find out whether the symptoms are a sign of cancer and, if so, what type of cancer it is.

## Treatment

Someone with cancer will usually have a doctor called an oncologist who supervises their care and works with them to decide how to treat the condition.

There are many different treatments depending on the type of cancer and how advanced it is. A cancer patient may need surgery to remove a tumour. Sometimes surgery will be used with chemotherapy and radiotherapy.

Chemotherapy involves an injection of powerful medicine to destroy the cancerous cells. Sometimes this is used to shrink the tumour before it's removed by a surgeon. Chemotherapy has a range of side-effects and can make people feel very tired and cause some people to lose their hair and to be sick.

Radiotherapy focuses high-energy X-rays on the tumour to help destroy it. Sometimes chemotherapy and radiotherapy are used together.

## Nursing

People with cancer need more care than just medicine, surgery or radiotherapy. They'll need practical, physical and emotional support which can be provided by specially trained and experienced nurses. Their role is to give advice and support to the person with cancer and they can also provide help to the whole family.

Once the person with cancer is at home, district nurses are responsible for helping and social workers may also be involved and can arrange for extra help in the home if someone is very ill.

## Caring for someone with dementia

Dementia covers a number of conditions which cause problems including memory loss, poor attention and difficulty understanding, communicating or problem-solving. Alzheimer's disease is one such condition.

These conditions are more common in older people and get worse over time. In some patients dementia occurs quickly but in others it takes years.

Lots of research is being done to find out what causes dementia and what might prevent it. One type of dementia (vascular dementia) is caused by blocked arteries stopping blood getting to brain cells.

Most people who have dementia experience memory loss. This can range from simple things (like forgetting what shopping they needed) to more serious things (like forgetting what year it is or who family members are). It's also common for some people to forget things from their short-term memory (like what they did yesterday) but remember things from their long-term memory (like the day they got married).

Mood swings can be a common symptom because parts of the brain that control mood and emotion are affected by the disease. Sometimes communication is difficult for people with dementia and they can also experience a lot of confusion.

As the dementia gets worse, it becomes harder to do everyday things, but there are a number of people who can help make things a little easier. District nurses help people in their own homes with medication and general nursing duties. Community psychiatric nurses are specially trained to deal with mental illness and can help both the person with dementia and the family who are helping look after them. Carers of people with dementia could also try talking to their family doctor, who may be able to help both the patient and their family.

Unfortunately, dementia cannot be cured, but medicine is available to help people's symptoms at various stages of the illness. A doctor or nurse should be able to provide carers with more information about this and whether it would help the person with dementia. Puzzles, memory games and even computer games can help with memory loss.

### Caring for someone who has had a stroke

A stroke happens when the blood supply to the brain gets interrupted or stopped temporarily. The cells in the brain begin to die as they're starved of oxygen and blood.

There are many symptoms of stroke, including weakness or numbness down one side of the body, problems talking or eating, difficulty understanding what other people are saying and severe headaches.

## Act fast

It's vital that someone who might be having a stroke gets help as quickly as possible, as this can make a big difference to how much damage a stroke causes. A person who has had a stroke will almost certainly be taken to hospital and assessed by doctors.

Many people who have had a stroke find they can no longer do some of the things they could before. They may be very forgetful and unable to remember things or people from before the stroke. Because of these changes, they may get quite upset or depressed. They may worry about how to do the things they used to be able to do. Many of these difficulties and worries can be helped by specialist staff at the hospital.

Strokes are most common in people over 65, but anyone who smokes, is overweight or has a family history of heart disease or diabetes could be at increased risk of suffering a stroke. Some people with irregular heartbeats may also be susceptible to strokes.

If the person is able to get to hospital quickly, drugs that dissolve blood clots can really help reduce the damage from a stroke. There's a range of medication which can help reduce a person's chances of having another stroke. These include drugs to lower someone's blood pressure or cholesterol levels. With some types of stroke, surgery may be needed to remove blood from the brain and repair burst blood vessels. With help, someone who has had a stroke may be able to learn how to lead an independent life again.

## Rehabilitation

There are lots of people who can help someone who's had a stroke. Physiotherapists are trained to help the person learn to do physical tasks again, such as picking things up or walking. They'll help the person who had the stroke become more independent again by giving them lots of exercises to do.

Speech therapists help with communication skills and talking. Occupational therapists will work out if the person who had the stroke needs special equipment to help them be independent and return to their home. Counsellors may be available to listen to and help the person come to terms with the physical and emotional effects of the stroke.

Caring for someone with multiple sclerosis hide

Multiple sclerosis (MS) is a condition that damages a person's nervous system, leading to pain, tiredness, dizziness and problems with walking, seeing and speaking.

There's no single list of symptoms and the illness can change from day to day, making it difficult in the early stages for doctors to decide if a patient actually has MS.

Scientists think genes play a part in it and that, in some cases, relatives of a person with MS may go on to develop it themselves. It's more common in colder countries and researchers also think other illnesses could trigger the disease.

There are three main types of MS:

Relapsing remitting MS. This is the most common form of MS. People have times when their symptoms are quite bad (known as relapses), and other times when they seem OK again (known as remission). These times can last for months and continue throughout a person's life.

Secondary progressive MS. This is when someone has periods of both relapse and remission but over time their condition gradually gets worse and some symptoms don't go away at all.

Primary progressive MS. This is when symptoms continue to get worse with no improvement or periods of remission.

Once someone has been diagnosed with MS, depending on what their symptoms are they could get help from many people, including:

Neurologists, who are doctors that deal with problems of the nervous system. They're responsible for treatment and medication.

Physiotherapists, who will help someone after a relapse learn how to use their body again. They might teach them exercises to build their strength up again.

MS nurses, who have specialised knowledge and training in helping people with MS and their families too.

Occupational therapists, who will help the person with MS to lead as independent a life as possible. For example, they could find out about specialist equipment or help with adaptations in the house.

Social workers, who can arrange a care package for the person and their family to help them cope with MS. They can also organise care workers to come and help at home. Social workers should also find out how everyone else in the family is coping and what help they might need.

There's no cure for MS, but if someone has MS their life can be greatly improved by managing the symptoms. Medicine called steroids can help somebody recover from a relapse and are usually given as part of a hospital treatment. For some people with MS, drugs can reduce the number of relapses they get. These can be taken at home by injection.

Caring for someone with cerebral palsy

Cerebral palsy affects movement and co-ordination and is caused by damage to the brain, either before or during birth. Sometimes a baby's brain doesn't develop, leading to some or all of the symptoms listed below. Sometimes problems during birth or an infection or head injury in young babies can cause the brain to become damaged, resulting in cerebral palsy.

Cerebral palsy affects people in a number of different ways. The most common symptoms are problems with muscle control and difficulties with co-ordination; difficulty sitting or standing without help; difficulty with eating, swallowing or talking, and problems with sight or hearing.

A range of treatment is available to people with cerebral palsy. This could include medication to help reduce symptoms such as twitching or jerking movements, or to relax stiff muscles. A speech therapist can help a child with cerebral palsy to speak or use sign language, and a physiotherapist will use exercises to help with stiff muscles and mobility problems. Surgery might help if problems with bones and muscles are causing someone pain.

Young carers: blindness or deafness

Sometimes a person is born with limited sight, or completely unable to see. Others may have no sight or limited sight because of an accident, an injury or an illness.

Even if the person has been blind for most, or all, of their life, there is still a high chance that they will need to help with some tasks. Filling out forms and going to new places are typical of how you might be able to help as a young carer.

The RNIB website has lots of useful information on helping people with sight problems.

### Deafness or limited hearing

Many people have hearing problems all of their life but others develop them as a result of an accident, an injury or an illness.

People who are deaf can often make adjustments to their lives so that they can cope with their hearing limitations but others may need more support. Young carers will often find that there are things they have to do to help such as speaking to people on the phone, communicating in shops, or answering the door at home. But some things, such as completing complex forms or signing in meetings can be stressful and you should not feel that you have to take this all on yourself.

There are also lots of things that everybody can do to make it a little bit easier to talk with people who have hearing difficulties - for example, the RNID website has a lot of suggestions.

### Young carers: learning disability

If someone has a learning disability, it means that they may find it more difficult to learn, understand and communicate. Learning disabilities are not a “mental illness”, but can be caused by some illnesses or problems before or during birth, or that develop during childhood or as the result of an illness. It is not always possible to tell what causes someone's learning disability.

People with learning disabilities may also need more help with everyday tasks but with the right kinds of help and support, they are often able to go to school, college and live and work completely independently.

### Autism and Asperger's syndrome

Autistic spectrum disorders is the name for a group of similar conditions including autism and Asperger's syndrome. Someone with autism or Asperger's might have difficulty in a number of different areas, including:

Social difficulties. They may appear confused or scared by people, especially people that they don't know. They may find it difficult to make friends and often don't like people coming into their personal space.

Difficulties with language and communication. They may find it difficult to speak, may choose not to talk or may talk a lot. They may also have trouble understanding words or faces.

Difficulties with their behaviour and using their imagination. Sometimes the world may not appear to make sense to a person who has an autism spectrum disorder and they may seem as if they are living in their own world. They may find it difficult to cope with change or new situations and like things to be done in a certain way.

Autism can affect people in lots of different ways. Nobody really knows what causes autism, but doctors are still finding new ways of helping people who have autism to learn skills and live happier lives.

## Down's syndrome

Each cell in the human body contains "chromosomes", which contain our genes. These chromosomes are copied when new cells are made. People usually have 23 pairs of chromosomes, but somebody born with Down's syndrome has an extra chromosome. This causes their body and their brain to develop differently although nobody is really sure why this happens.

People with Down's syndrome tend to look different and tend also to be shorter than average. Almost half of people affected have heart defects, some of which can be treated, some of which can't. They may also have hearing or sight problems and later in life there's also an increased risk of diseases such as leukaemia and Alzheimer's disease.

People with Down's syndrome may have only a moderate learning disability but others may have a severe learning disability. People with Down's syndrome used to have a shorter life expectancy than other people, but now most people with Down's syndrome can expect to live into their 60s.

## Young carers and mental illness

A mental health condition is just like any other kind of illness that can be treated with proper medical help. It is quite common for people to experience a

mental health problem and many people will be affected at some point in their life.

## Anxiety

When people are scared, nervous or excited, their bodies release a chemical called “adrenaline” which makes their hearts beat faster, and can make them feel hot or sweaty. Occasionally, when someone's anxiety suddenly feels as though it's too much to cope with, their body releases lots of adrenaline very quickly. This is what's often described as a "panic attack" and although it can be frightening, panic attacks are not dangerous and will go away after a while.

Many people get anxious at times and have feelings of being worried, scared or frightened. However, some people have such feelings of anxiety, even at the smallest things, that it can make life very difficult. This is often called “generalised anxiety disorder”.

To help with anxiety and panic attacks, it is worth chatting to a doctor who may be able to prescribe medication. People also find that counselling, yoga, relaxation exercises help as well.

## Depression

Depression can cause people to feel sad, tired and have trouble sleeping. It can make life feel very difficult and even the simplest of things can cause a lot of worry. Some people feel constantly depressed whilst for others depression can come and go in “cycles”. Medication prescribed by a doctor and talking to someone (like a counsellor, a psychotherapist or a community psychiatric nurse) can be a big help for people suffering with depression.

As a young carer, you can talk to the person with depression and ask them what type of treatment they are having and how their condition affects them. If you feel depressed (because of the worry and stress of caring for someone) then it is worth you talking to someone yourself. You can also get information from the Young Minds website.

## Obsessive compulsive disorder

Obsessive compulsive disorder - often called OCD for short - is a mental health condition which causes people to have the recurring thoughts and ideas that won't go away and that people think that they need to act upon. For example, someone with OCD may wash their hands a lot because their mind is telling them that their hands are dirty. They may have to make sure that things are placed in a certain order because they suffer from a lot of anxiety and worry if they think things are out of order.

People suffering from OCD may not even know the reason why they do things in a certain way, it's just that it's important to them that they do. It is important to remember that medication and counselling can be a good way of helping people with OCD.

## Schizophrenia

Schizophrenia is an illness that stops people from telling what is real and what is not. Sometimes people with schizophrenia might hear voices or see things which aren't there. Some people with schizophrenia might be very confused and behave strangely.

People with schizophrenia can get help with their condition by taking regular medication and getting care and help from a doctor, mental health worker or community psychiatric nurse. Sometimes people with schizophrenia might need to go to hospital for a while so that they can be looked after properly.

There's more information about psychosis and other mental health issues on the Young Minds website.

## Self-harm and suicidal behaviour

Self harm is when people injure or harm themselves on purpose and there are a number of reasons why they might do this. Sometimes it's because they are really sad or depressed and by hurting themselves they feel that they are releasing themselves from some of the pain and distress that they feel inside.

Some people might want to punish themselves or do it because they hear voices telling them to. Some people find things so difficult that they start to have thoughts about killing themselves. For many people, these thoughts are very secret, but others might talk about killing themselves, and perhaps even make threats about it.

Young carers who are looking after someone who self harms or feels suicidal might find it really upsetting to know what is happening. It's important to remember that they are not doing it because of anything the young carer has done. They do it because of how they feel inside.

If you care for someone who self harms or feels suicidal, you should try to talk to them or to talk to their doctor, psychiatrist, or counsellor (if they have one).

### Common questions

What will happen if I leave them on their own?

You will never be able to be with the person you are looking after for 24 hours a day. The best way to keep them safe is for them to get help from an expert, like a doctor, nurse or social worker.

You could help by writing a list of people to call in an emergency, or things the person could do to cope if they feel stressed.

Think about other members of the family, friends or neighbours who are around and ask them for help too. If you are at school or college, you could talk to a teacher and see if they will let you have access to a phone. This could help you and the person your care for to feel more relaxed when you're apart.

Will it happen to me?

Even though some people may develop a mental health condition similar to one that their parent has, it is not very likely that this will happen.

Although genes may play a part in some mental illnesses, there are usually other things that contribute such as stress. Even if you have heard that a family member's illness is "genetic", this doesn't mean that you will definitely be affected too.

All young carers who are caring for someone else need to take care of themselves too. Getting exercise, eating properly and sleeping enough can all help, as does talking to others in a similar situation and taking time out to relax.

### Young carers: drugs or alcohol misuse

Many adults drink alcohol, but it can become a problem if they begin to misuse alcohol by drinking it too often or in too great a volume. People can find it very hard to stop drinking alcohol and this is known as "an addiction".

People can also become addicted to drugs. We often think of people being addicted to illegal drugs like cannabis or cocaine, but people can also become addicted to drugs they have on prescription, such as painkillers or sleeping pills.

Life as a carer of parents who are misusing drugs and alcohol can be very difficult. The person using drugs or drinking might try to hide their addiction from their closest friends and relatives and may even get annoyed if people try to talk to them about it. Their behaviour can be quite unpredictable at times - they can get angry or scary (especially if they are craving alcohol or the drugs they take).

Alcohol and drug addiction are like illnesses – they are not anyone’s fault and it can be hard to stop someone from taking drugs or from drinking. Talking to someone who misuses drugs or alcohol can be difficult – especially if the person using drugs or drinking doesn’t feel that they have a problem. Choose a time when the person has not been drinking or taking drugs to chat about the situation and explain how you feel about the situation.

### Getting help with alcohol or drug problems

People using alcohol or drugs may worry about what will happen if they ask for help. There are lots of people who can help. A good place to start is with the local family doctor (DOCTOR). They will be able to make a referral to a specialist drugs and alcohol team.

Doctors might also suggest that the person using drugs and alcohol should get some help from social services. Some people worry that social workers will take children away from their parents, but this is unlikely to happen as it is a last resort if social workers feel children are at risk of being seriously harmed. Social workers normally simply provide the family with some extra support and help.

### Treatment and support

The drug and alcohol team might suggest that the person using drugs and alcohol has a “detox”, which helps the person with the addiction to stop using drugs or drinking. They may go to see a local counsellor to help them work through their problems. Alternatively, they might go to stay in a rehabilitation centre. Support groups, such as Alcoholics Anonymous or Narcotics

Anonymous, are also useful for the person with the addiction to meet others who are in a similar situation.

You should ensure that you get help for yourself too. Sometimes dealing with drugs and alcohol (and getting better from them) can take months, or years. You could talk to a trusted friend or teacher, another member of your family.