

Caring for someone with Lupus



This information leaflet has been produced by LUPUS UK
© 2015 LUPUS UK

LUPUS UK is the national charity caring for those with systemic lupus erythematosus (SLE) and discoid lupus erythematosus (DLE), supporting people as they develop the symptoms prior to diagnosis and those already diagnosed.

You can help by taking up membership
For more information contact:

LUPUS UK, St James House, Eastern Road,
Romford, Essex RM1 3NH
Tel: 01708 731251

www.lupusuk.org.uk

Reg. charity nos 1051610, SC039682

LUPUS UK is certified under the requirements of the Information Standard.



Please contact National Office should you require further information on the sources used in the production of this booklet or for further information about lupus. LUPUS UK will be pleased to provide a booklist and details of membership.



Our thanks go to Action For M.E. for allowing us to create this booklet by adapting their booklet 'Caring for somebody with M.E.'

We're also very grateful to Breast Cancer Care for allowing us to adapt some text from their booklet, 'Talking with your children about breast cancer' for our own use.

Thanks also go to those who kindly submitted their case studies and advice for inclusion within this guide.



About this Booklet

This booklet is intended to provide information and guidance to anyone who has become a carer of someone with lupus.

This booklet does not constitute or replace medical advice and should be treated as such.

Around six and a half million people in the UK are carers and it is estimated that over two and a half million people become carers every year.¹ A carer can be a partner, relative or friend of any age, who looks after someone unable to look after themselves on an unpaid basis.

Contents	Page
1. Understanding Lupus	2
2. Becoming a Carer	4
3. Looking after Yourself	9
4. Welfare Benefits	12
5. Pointers and Tips from Other Carers	14
6. Useful Contacts	15

¹ 'Facts about Carers' - Carers UK, May 2014



1. Understanding Lupus

What is lupus?

SLE, also known as 'lupus', is a long term condition that causes inflammation in various parts of the body. It is an autoimmune disease. Normally the body's immune system helps protect against infection but in lupus, the immune system does not work properly and produces autoantibodies that attack healthy cells and tissue.

Lupus can affect almost any part of the body including the skin, joints, blood vessels, and organs such as the heart and kidneys.

People with lupus have symptoms that can range from mild to severe, and may come and go over time. Some of the most common symptoms include;

- Severe tiredness/fatigue
- Weight loss
- Fevers
- Skin changes (including a red 'butterfly' rash across the cheeks and nose or other exposed areas and scaly rashes that can appear on areas not exposed to sunlight)
- Painful, stiff or swollen joints (arthritis)
- Poor circulation in the fingers and toes which causes them to become pale (Raynaud's)

SLE is the most common form of lupus, but other forms include Discoid Lupus (DLE) which is generally a benign disease affecting the skin and rarely the internal organs and Drug-induced Lupus (DILE) which can occur during the administration of drugs in susceptible individuals. Further information about these forms of lupus can be obtained from LUPUS UK.

Who gets lupus?

Anyone can develop lupus but it is more common in young or middle aged women than men. It is also much more common in black and Asian people than in white people.

What causes lupus?

The causes of lupus are not fully understood but are likely to be due to a combination of genetic and environmental factors. Lupus can cause periods of illness ('flares') and periods of feeling comparatively well with no/fewer symptoms or signs of disease ('remission'). It is not infectious and cannot be caught from another person.

How is lupus diagnosed?

There is no single test for lupus. The diagnosis is usually made based on



symptoms and a number of special blood tests which measure autoantibodies and levels of inflammation. These include;

- ANA (anti-nuclear antibodies)
- DNA antibodies (anti double-stranded DNA antibodies)
- Complement levels (C3 & C4)
- Blood count - which looks at levels of different blood cells
- ESR - which looks at inflammation levels

For further information about how lupus is diagnosed, LUPUS UK can provide the booklet, "The Diagnosis of Lupus".

How serious is lupus?

Lupus is different for each person. Many will experience a mild flare which could affect various joints, skin and cause fatigue. With time, treatment may help improve these symptoms and this is when the disease is said to be in remission. Some patients only experience one flare, however, others may experience periodic increased disease activity followed by periods of remission. While these milder flares often disrupt normal activities and patients may need to make certain adaptations to their lifestyle (to make life easier at these times) they do not cause a threat to internal organs. However, despite treatment some patients may still only feel some improvement and activity of the disease continues at a low level. For a smaller group of patients lupus is more serious and despite the use of various treatments the disease remains difficult to control. Major kidney, central nervous system or vascular involvement of the disease require a more intensive medical follow up and treatment, and can have a serious impact on patients' health. With new treatments and care pathways outcome results have improved.

Lupus can be a very unpredictable condition and may flare up with little or even no notice. The frequency and severity of these flares often differs between patients. Over time some patients may be able to identify environmental triggers for their flares such as exposure to sunlight or stress. By controlling these factors or being more aware of the onset of a flare, they may be able to minimise their impact. However, some flares may happen without an obvious trigger.

Extreme fatigue is one of the most common symptoms of lupus and it is often described as the most debilitating. Lupus fatigue is different from normal tiredness so it is important to discuss this with your partner and agree on a good way to communicate how they feel from day to day. It is likely that they will not be able to do as much as they used to do, so some changes will need to be made. Rest is very important for people with lupus, but it is also a good idea to try and incorporate some light exercise where possible. In many people with lupus the extreme fatigue and reduction in activity can make them even more tired and lethargic.

Telling others about lupus

One of the most difficult things people with lupus and their carers have to deal with is a lack of understanding about the condition and a disbelief about the seriousness of lupus. More people are better informed than in the past, but it is still not uncommon to experience a lack of understanding and support when explaining that the person you care for has lupus.

Further information

For more detailed descriptions of the condition and ways of coping with symptoms, LUPUS UK has a wide range of booklets and leaflets available from our National Office which can be ordered by calling 01708 731251. Alternatively they can also be downloaded from our website at www.lupusuk.org.uk

“Contact LUPUS UK first to find out about the condition from those that know the facts; Books and random internet sites can just confuse the issue.” Larry

2. Becoming a Carer

Taking on a new role

“It is very hard at times. I have had to become much more organised with appointments and medication. Caring for him isn’t as hard now as we have a routine, plus it helped that I used to work in a care home.” Katie

You may have found yourself in a caring role suddenly, or perhaps it has gradually increased over the years. Either way, your role and that of the person you are caring for has changed. In order to cope with these changes your relationship will need to adjust. This can be very difficult at first as both of you struggle to reassign yourselves, facing many challenges along the way.

Both of you need to work together in order to make the most of your new situation and move towards a better quality of life. This means accepting the illness and its restrictions.

“I’m not sure you “take on the role”; you just do your best for the person concerned (not always easy I admit), and perhaps be thankful that it is not you that has received the diagnosis and all the potential future health problems that may come with it.” Larry

Your feelings

“In a strange way it was a relief that there was (eventually) a diagnosis for all the various problems that my wife had suffered over the years and that we had now

entered the system where she would be dealing with consultants rather than the local GP. Even if that prospect was less than appealing, it did mean that specific professionals who were familiar with lupus would be dealing with her conditions and monitoring her going forward.” **Larry**

Becoming a carer can evoke many emotions in you that are difficult to accept. It is not unusual to feel a sense of loss for your past life or bitterness towards your new situation. These are perfectly natural feelings that you do not have to feel guilty about. You may not be the person with lupus, but you can still feel just as trapped, lonely and frustrated.

Acknowledging your feelings and discussing them is a vital step in the caring process and can be very helpful in developing and maintaining your new relationship.

You may find it helpful to talk through these emotions with someone. LUPUS UK has some carers who volunteer to be telephone Contacts for the charity. You can find contact details for them in the back of each edition of LUPUS UK's News & Views magazine, or by calling LUPUS UK National Office on **01708 731251**.

“I was devastated as I had seen the impact lupus could have on everyday life and I knew how unwell my Nan could be.” **Donna**

“I was in denial for some time, as the thought of something that would affect us so strongly for the rest of our lives was too much to bear. As the symptoms became managed (to some extent) through medication and we learned how to change our lifestyle (in terms of where we could go/for how long/what we had to take) to cope with having lupus, it became a lot easier to digest.” **Nicholas**

Family

“Our family was affected a lot. At the time of my wife’s diagnosis our daughters were eight and four years old and lupus gradually limited more and more of our family activities. At times it has dominated our lives. A person with lupus can be affected by so many different problems, it can be very demoralising for everyone - as can the fact you never know when you get up in the morning how well they will be that day or which of their problems will be more of an issue than normal, so it is difficult to plan anything.” **Anon**

Try to involve your family right from the start. Explain the situation to them; tell them about the condition and how, for the time being, you will need to spend more time with the person who has lupus. If you try and include them in caring, you will be spending time together, whilst also sharing the responsibility.

Sometimes family members may have difficulty understanding lupus and how it

can affect somebody, especially if the person with lupus doesn't appear unwell. It may be helpful to use this booklet as well as other resources which are available from LUPUS UK National Office.

Explaining lupus to children

If you are the partner of somebody who has been diagnosed with lupus and you have children, you may be debating how and when you are going to explain it to them. This can be intimidating and difficult and what you tell them may depend on their age and how you usually talk with them about illness and other issues in the family.

There are no set rules about how and when it is best to tell them. It is worth considering that the longer you leave telling them, the more likely it is that they will realise that all is not well and start worrying and guessing what it might be. Explaining the diagnosis to your child/children alongside your partner may help them remain more calm and confident during a vulnerable and emotional time for themselves. By staying calm and confident (even if you don't feel it inside), it will help your children feel less upset and panicky.

It's a good idea to keep talking with your children regularly so that they feel involved and informed and are able to ask any questions. You may need to repeat explanations, especially to younger children.

Under six

What you say to very young children will depend on the words you normally use for feeling ill. You don't want to frighten them or overload them with information, but you may decide to tell them that the person with lupus is poorly and tired. As well as talking, you may want to show them what is happening using dolls or teddies or by drawing pictures. Most young children don't like changes to their routine and may worry about being separated from their parent. If the person with lupus needs to go to hospital then the child needs to know that they will be back soon, and they won't be left alone or with someone unfamiliar. With very young children one of the most important things to make clear from the start is that their parent's illness is not their fault. Young children sometimes blame themselves for what happens to the adults in their lives and they may link the lupus to something they've said or done. This can make them feel guilty so they need to be reassured, whether or not they tell you their fears. They may also worry that they might catch lupus, like chicken pox or a cold, so you should explain that this is not the case.

7-12 Years

It is worth preparing children of this age for the symptoms and side-effects from treatment that their parent with lupus may experience. These side effects could



include; extreme tiredness, nausea, sun sensitivity and hair loss. You can ask them to let you know what they want to know about the diagnosis or treatment when they want to talk. Most children study the human body at primary school and will have some basic ideas about cells and the different parts of the body. You may want to look at some factual information with them.

You should encourage the child to talk about their feelings. School-age children are more aware of how their parent's illness affects them, and they may be very anxious or resentful. Routine is just as important for them as for younger children. They will want to know that the detail of their daily lives will not change dramatically. Who will take them to school? Who will care for them after school? Who will cook their tea?

Sometimes children can feel worried about changes in their parent's appearance and what others may say or think. If the person with lupus experiences hair loss or rashes you can talk about this and how to relieve their anxiety.

Once the person you care for has a diagnosis, telling your children's teacher/s and possibly the school nurse may help them prepare for answering questions or giving them extra support. Most schools will also have a member of staff who is responsible for pastoral care.

"My children are seven and four years old. As they have aged they have noticed that on certain days I'm in pain and sometimes I cry out in pain when moving or getting up from a chair. I was just honest with them and told them, 'Some days Mummy is sick and her bones are achy, tired and sore'. I've shown them my rashes and the creams I apply. My husband also tells the kids, 'Mummy needs to rest now, she's very tired and if she doesn't go to bed she will get sick'. They are also aware of my medication and know I take meds every morning to keep me better. My eldest son even tries to help me up the stairs when I'm sore which he enjoys because he feels he is helping me. On my good days of course I play with them and try to do normal things." **Sophie**

"I was diagnosed nineteen years ago and had a daughter thirteen and a half years ago. I've always told her from the time that she was tiny that there are some things that Mummy can't do and days when she feels really ill. My best advice to get children to cope and understand is compromise; If you are feeling good, do something they enjoy (a trip out, go to park) but they soon understand that on bad days Mummy is slower and can't do much. Don't hide it from them." **Helen**

Teenagers

Whilst most teenagers are unlikely to know about lupus, it's useful to find out if they do and how much they may know. They may know friends or a friend's



relative who has been affected by lupus. Teenagers may want more detail about lupus and your treatment but they may also prefer to find out about it on their own. You may want to point them towards reliable sources of information such as LUPUS UK's booklets and website. It is worth explaining to them that lupus is a very individual condition and so not all information they find online will apply to their parent's case.

Some teenagers may appear unconcerned about the whole thing and, like some adults, try to pretend it's not happening. Others may be emotional and withdrawn. It's important that this isn't taken personally and they are allowed to express themselves. Whilst they may not want to talk to anyone at first, they may want to discuss it and ask questions of someone later.

Teenagers may be anxious that they will get lupus too, particularly if they have heard that it can run in families. In fact, as a result of so many genes being involved in the development of the disease (only half of which are inherited by a child from one parent with lupus), and because environmental triggers have to occur during the life of the individual to make the disease appear, it is not common for the children of people with lupus to have it too. Most studies have shown that about 1 in 20 people with lupus will have a close relative (mother, aunt, sister, brother; less often father or uncle) with lupus and you may want to reassure your children of this.

One thing that most teenagers have in common is that they are easily embarrassed - especially by their parents. Appearances are often important to them and it may be important to discuss potential changes in appearance due to lupus and treatments such as hair loss, rashes and weight gain (from steroid treatments).

It is normal for teenagers to be struggling with feelings of wanting independence and to break away from their parents or family, and they may not know how to negotiate with a parent who needs to depend on them for a change. They may feel torn between wanting to be there and dealing with their own lives or problems, such as relationships, friends and exams. It may be helpful to talk with your child's teacher or form tutor so they are aware of the situation. If your child is preparing for exams, the school can apply to the exam board for special consideration. This will only happen if you request it.

Work

If you are working as well as caring, you will effectively be juggling two jobs and this can be very stressful and demanding.

It could be worthwhile finding out if your workplace has a policy to support carers. Handing your employer some literature about lupus may also be

beneficial in helping them to understand the condition and the constraints you are under.

You may be thinking about leaving work altogether in order to care full time. This is a decision that needs to be thought through carefully as giving up work will mean a drop in your income and in the time you will have away from caring.

“In the early days I managed to balance work, home life and caring well, but as my Nan’s illness progressed it became harder to balance and I eventually decided to take voluntary redundancy to enable me to spend the required time with her. Even then, balancing my time with my own family and providing care was extremely draining but I would not have changed anything.” **Donna**

“Luckily my two previous employers were large companies that offered a good measure of flexibility with regards to the care needed during work time. As long as time was made up and additional “effort” was put in, neither had any problems with time off for hospital visits, or indeed those occasions when it was necessary to return home when I was needed.” **Larry**

“My wife comes first and I made that clear to my employer. They were fantastic and let me work from home sometimes as needed and are very flexible about my working hours.” **Anon**

If you do decide that leaving work is the right option for you, research the types of welfare benefits that you and the person with lupus may be eligible for. Read our introduction to benefits on page 12 and contact Carers UK for a full list of potential benefits for carers (see page 15).

3. Looking after Yourself

The simple truth is that in order to look after someone well, you need to look after yourself. Your needs are just as important as theirs.

You may have found that your quality of life has suffered due to your new role and it can be all too easy to fall into a pattern where your needs are set aside on behalf of the person you care for.

It is in fact a lot easier to cope with the pressures of caring if you are also caring for yourself. By maintaining both your emotional and physical health, you will be able to care to the best of your ability.

Consider letting your GP know you are a carer as they can often be a valuable source of information about medical and community services and support.



Accepting Help

Coping with dependence is a huge responsibility and it can be difficult to overcome feelings of duty towards the person you care for. However, an essential part of self-care is to get support from others and this is especially important when you are living in a situation that is emotionally and physically demanding.

Accept help from your friends and family when it is offered to you. If you say you are managing, they may not think to ask you again, which could result in you missing out on an invaluable source of support.

Sources of Support

Your GP or local authority Social Services department should have information about the help available to you in your area. Your local lupus support group or carer's centre may know of other carers near you, with whom you can talk and exchange ideas. LUPUS UK has some carers who volunteer to be telephone Contacts for the charity. You can find contact details for them in the back of each edition of LUPUS UK's News & Views magazine, or by calling LUPUS UK National Office on 01708 731251.

"It is an important factor that you do 'look after yourself', and it is interesting to note that more than one consultant has asked me '...and how are you?', so the carer's wellbeing is obviously a consideration when dealing with the actual patient's condition." Larry

"When my husband was in hospital I didn't look after myself. I didn't eat properly for about six weeks so my mum and step-dad looked after me. I still struggle to find time and money for myself but Carers in Bedfordshire helped as they gave me support and a grant to go get my hair done and find time for myself." Katie

Taking a Break

It is vital to take breaks away from the person you are caring for. Having regular time to relax and to do something that is just for you is crucial in recharging your batteries and maintaining your own life outside of caring. If you don't currently have a hobby, you might enjoy finding a new activity or interest that can occupy you during quiet times when you are needed less often. It is important not to become isolated and to maintain relationships with friends and family. This will help provide you with additional sources of support at any time when you may need help yourself.

If you are concerned that the person you care for will feel uneasy having someone else around them, try to think of different ways that could take the pressure off you. For example, even something as straightforward as a friend preparing dinner could give you half an hour to spend by yourself.

You may want to consider hiring home-help or taking a short break either with or without the person you care for.

“My favourite hobby is fishing and I try to do this once a fortnight. Jane has two older children that are more than happy to help if I need a break.” Neil

The Margaret Champney Rest and Holiday Fund gives small grants to carers, usually to give them a complete break whilst the person they care for is receiving respite care. All applications must be through a social worker, community nurse or similar professional agency. For information, write to: The Gate House, 9 Burkitt Road, Woodbride, Suffolk IP12 4JJ. Tel or fax: **01394 388746**. Email: **info@ogilviecharities.org.uk**

Community Care for Both of You

The person you care for may be entitled to a community care assessment from Social Services. This would look at the services that may be available to them and assess their eligibility. Some of the help that may be available could include aids or adaptations, help with personal care, day-to-day living or help with meals. Social Services should also look at your ability to provide care to the person having the assessment.

If you are caring for someone you can also request an assessment in your own right. This is to assess your own support needs as a carer and your continuing ability to provide care. Following an assessment the person that you care for may be able to get some extra help through social services and you may be able to get a break from caring.

If the person you care for is assessed as needing services, they may be able to receive direct payments. This means they are paid a sum of money that they can use to hire their own care. In some cases they may be able to employ their existing carer but direct payments cannot usually be used to employ a spouse, partner or close relative who lives in the same household (if you are in this position seek advice as there can be exceptions to this).

As a carer you may also qualify for direct payments in your own right (only in England and Wales). These are designed to give flexibility and can be used to help you sustain your caring role.

Contact your local authority Social Services department to request an assessment. You could also ask your GP to make a referral.



4. Welfare Benefits

What are you entitled to?

Benefit rules are very complex and subject to change so please use the following as a general guide and seek advice about anything you are unsure of. If you are considering giving up work to become a full-time carer it is essential to seek advice about the benefits that you may be entitled to.

"I am receiving Carer's Allowance and my husband claims ESA and PIP. It's a lot better than last year when all we were living on was statutory sick pay and working tax, which was not a lot." Katie

Carer's Allowance

This is the main state benefit available to carers. To qualify:

- You need to be caring for someone for at least 35 hours per week
- The person you care for needs to be getting the middle or high rate care component of Disability Living Allowance, Attendance Allowance or Constant Attendance Allowance or the daily living component of Personal Independence Payments.
- You need to be 16 or over
- You need to be eligible to claim UK benefits and meet certain other residential criteria
- You cannot be in full time education
- You can be employed, but you are only allowed to earn a certain amount - this increases each year

Claiming Carer's Allowance can affect the benefits of the person you care for. If they receive the severe disability premium or addition, seek advice before claiming.

If you are already receiving certain benefits you will not actually be paid Carer's Allowance but it can still be worth claiming as you may be able to get the carer premium or addition. This is an extra amount of money paid on top of certain means-tested benefits.

NB. This booklet does not cover all the benefits affected by Carer's Allowance. Contact a carers organisation or a benefits advice agency (see pages 15 and 16) for more details.

Other Benefits

In addition to Carer's Allowance you and the person you care for may also be eligible for other benefits such as Income Support, Employment and Support Allowance, Job Seekers Allowance, Pension Credit, Housing Benefit, Council Tax Benefit and Personal Independence Payments or Disability Living Allowance (this

list is not exhaustive).

If you have dependent children you may be able to get Child Tax Credit. If you have a mortgage you may be able to get help with this through Income Support or have income related Employment and Support Allowance.

Each person's circumstances are different and so other benefits may be available to you that are not listed above.

Eligibility for benefits also depends on your family circumstances, any savings you have and in some cases your National Insurance record as well as your status in the UK.

Health Costs

If you are receiving certain benefits you and the person you care for will be entitled to free prescriptions, dental care, sight tests etc.

If you are on low income you may also qualify for some help with health costs.

For further information contact the NHS Low Income Scheme on **0300 330 1343**.

5. Pointers and Tips from Other Carers

“Just be there, be the voice if needed. Do what you can, learn as much as you can, never give up hoping for a cure, spread awareness, even if it’s hard from time to time. Be proud and enjoy the small things in life, go to the movies, to the restaurant etc.”

Charlotte

“Be organised. Know your information and what is available out there. I learned the hard way; only having citizen advice for help and they pointed me in the right direction. Stay strong when there is a good day - make the most of it and always talk.” **Katie**

“Try to get members of the extended family (and friends etc.) to read the information leaflets about the condition, and try to explain how lupus affects the body. This is possibly one of the most difficult things to get accepted, especially since the person with lupus will require their support in the future as well.” **Larry**

“Ensure that the person with lupus attends all of their medical appointments, and has the practical support to do so. This is especially important with lupus, as the condition can cause serious physical and mental problems as time goes by and should be regularly monitored by medical professionals.” **Larry**

“I believe that if you love someone you will do the best to care for them and make their life as comfortable as possible. It isn’t always easy and sometimes takes its toll on both of us, but Jane didn’t ask to be given this disease. We just live with what we’ve got and make the most of it.” **Neil**

“Try to be understanding and compassionate. There will be times when they get upset at you for no reason or times when they need to rest but there are things that need to be done. I can’t begin to understand how my wife and son feel on a daily basis, so I do my best to cut them some slack if they don’t feel 100% (which is most days). Understanding that this is a lifetime illness is also important, and understanding that it does require a lifestyle change. This lifestyle change is mostly in how we think (we may need to plan more or pack more) and not too hard once it becomes habit, but it goes a long way to the quality of life that we live.” **Nicholas**

“Try to stay positive and take breaks. Insist on getting a specialist nurse as well (if possible) as they can offer more support than anyone.” **Donna**

“When lupus is not affecting you too much, live every day as if it is your last. When it gets worse, keep getting out and about. Keep friendships going. Voice your concerns and worries with those who can help. Attend medical appointments together - two heads are better than one. Don’t be afraid to ask for help.” **Anon**

“Don’t panic you can handle this. Just take one day at a time.” **Anon**

6. Useful Contacts

Carers Organisations

Carers UK - www.carersuk.org

Information and support on any issue for people caring for friends and relatives. Extensive details of the benefits available to carers and the people they are caring for.

CarersLine: **0808 808 7777** (Wed & Thurs 10am-12pm, 2-4pm)

England tel: **020 7378 4999**

N. Ireland tel: **028 9043 9843**

Scotland tel: **0141 445 3070**

Wales tel: **029 2081 1370**

Email: **advice@carersuk.org**

Carers Trust - www.carers.org

Offers useful information and support for all unpaid carers throughout the UK.

Carers Trust, 32 Loman Street, London SE1 0EH

England tel: **0844 800 4361**

Scotland tel: **0300 123 2008**

Wales tel: **0292 009 0087**

Fax: **0844 800 4362**

Email: **support@carers.org**

Volunteering Matters - www.volunteeringmatters.org.uk

Recruits and trains volunteers to help individuals in need of support.

The Levy Centre, 18-24 Lower Clapton Road, London, E5 0PD

Tel: **020 3780 5870**

Email: **information@csv.org.uk**

The Margaret Champney Rest and Holiday Fund

www.theogilvietrust.org.uk

Organisation that gives small grants to carers.

The Gate House, 9 Burkitt Road, Woodbridge, Suffolk IP12 4JJ

Tel: **01394 388746**

Email: **info@ogilviecharities.org.uk**

Government Information

Carers and Disability Benefits

www.gov.uk/browse/benefits/disability

Government site for carers including advice on support services, employment, money, work and health.

NHS 'Looking After Me' course (England)

www.selfmanagement.org/our-courses

A free course for adults who care for someone living with a long-term health condition, run by tutors who are themselves carers. Courses are limited to certain areas, so contact 'Self Management UK' to check availability where you live.

Tel: **03333 445 840**

Email: hello@selfmanagementuk.org

Civil Legal Advice - www.gov.uk/civil-legal-advice

Tel: **0345 345 4345**

Advice on Welfare Benefits

Carers UK (See page 15)

Citizens Advice Bureau

See your local telephone directory or go to www.citizensadvice.org.uk for details.

Benefits Calculators

Independent benefits calculators-Find out what benefits you can get and how to claim

<https://www.gov.uk/benefits-calculators>

Tax Credit Office

Tel: **0345 300 3900**

Support for Parents

Contact a Family - www.cafamily.org.uk

Support and information to parents of children with any disability or long-term health condition, including rare disorders.

209-211 City Road, London EC1V 1JN

Helpline: **0808 808 3555** (Mon-Fri 10am-4pm, Mon 5.30-7.30pm)

Email: info@cafamily.org.uk

Family Lives - www.familylives.org.uk

Provides a helpline for anyone parenting a child or young person in need of support.

520 Highgate Studios, 53-79 Highgate Road, London NW5 1TL

Helpline: **0808 800 2222** (24hr)

Support for Older People

Age UK - www.ageuk.org.uk

Age Concern and Help the Aged joined forces in 2010 to form Age UK, including Age Scotland, Age Cymru and Age NI.

England tel: **0800 169 6565**

Northern Ireland tel: **0808 808 7575**

Scotland tel: **0800 470 8090**

Wales tel: **0800 223 444**

Anchor Trust - www.anchor.org.uk

Not-for-profit organisation dedicated to helping older people live safely, securely and independently.

2nd Floor, 25 Bedford Street, London WC2E 9ES

Tel: **0808 274 1291**

Independent Age - www.independentage.org

Advice and information for older people, their relatives and their carers.

18 Avonmore Road, London W14 8RR

Advice Line: **0800 319 6789** (Mon-Fri 10am-4pm)

Email: charity@independentage.org



Publicity materials, leaflets, posters, a dvd for the newly diagnosed, media releases and more are always available from the charity's National Office for better awareness about lupus in clinics, hospitals and public places.