



Becoming a carer is frequently a role that evolves due to prevailing circumstances over which you have little control. In the case of looking after someone with MND your role as carer may have started long before the person you care for was given a diagnosis. Unless you have deliberately sat down and planned things you are probably pretty much just taking things day by day right now.

According to the charity Carers Scotland, there are 6.5 million people caring for an ill, frail or disabled family member or friend in the UK. People do not always recognise themselves as carers: they would probably say "I'm just being a husband, a wife, a mum, a dad, a son, a daughter, a friend or a good neighbour." In Scotland there are 788,000 unpaid carers. 3 in 5 people will be affected by caring responsibilities at some point in their life. Without the right support, the personal cost of caring can be high with many carers experiencing poor health, poverty and disadvantage.

These facts illustrate the importance of making early positive decisions about identifying yourself as a carer who looks after someone for more than 35 hours per week and finding out about entitlements rather than simply taking each day as it comes. In some circumstances Carer's Allowance might be payable to more than one member of a household for looking after the same person.

Carers are a substantial proportion of the population and their needs are of concern to politicians and civil servants. In 2001 a

question was included in the national census form to identify how many people identified themselves as carers and in 2002 the Scottish Parliament passed the Community Care and Health (Scotland) Act. In addition to the better publicised "free personal care for the elderly" the Act also set out the Executive's policy in relation to carers:

*"To recognise and support carers, in order to achieve good outcomes for carers. Good outcomes for carers will occur when:*

- *the carer is able to cope better with their caring role;*
- *the carer gets a regular break from caring;*
- *the carer is better informed and more knowledgeable about their caring role and the needs of the person they care for;*
- *the carer feels valued, supported and listened to."*

In order to realise these ambitions the Act entitles "Substantial and regular adult carers" to an assessment of their ability to care ("carer's assessment"), independent of any assessment of the person they care for." For the first time, young carers under 16 have the same rights to an assessment. Both the carer and the person cared for are entitled to refuse an assessment under the Act, but as the above figures show both might benefit financially.

The 2001 Act requires Local authorities to ensure carers are made aware of this right and are also required to take account of the contribution of carers, and

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the views of the person in need and their carer, before deciding on services to provide to a cared-for person.

Scottish Executive Ministers required NHS Boards to draw up carer information strategies to inform carers in contact with the health service of their rights under the new legislation.

The purpose of the carer's assessment, if it is requested by the carer, is to establish what level of care the carer is willing and able to provide, and to determine whether their caring role is sustainable; to determine what resources the carer needs to help them in the caring role and to maintain their own health and wellbeing, and to decide how these resources can best be provided. Don't be put off by the word 'assessment'. It is not a test about how good you are at caring. It is to work out what can be done to make life easier for you. No one will judge you.

The assessment (in Scotland it is called an 'Adult Carer Support Plan', though it is still referred to as a care assessment) should also identify the care provided by a carer and the carer's views so that they can be taken into account before the local authorities decide what package of care to provide to the cared-for person. A carer's assessment is free and following the assessment a copy of the outcome of your assessment will be sent to you, with details of the support the council can offer to meet your assessed needs. This may include support that will benefit the person you care for and also you as their carer. It may also include other things that will benefit you directly.

The 2016 Carers (Scotland) Bill received unanimous support in the Scottish Parliament and was passed on February

4, 2016. The new Carers (Scotland) Act will be commenced in 2017-18.

The Act extends and enhances the rights of carers. Provisions in the Act will ensure better and more consistent support for carers and young carers so that they can continue to care, if they so wish, in better health and to have a life alongside caring. At the time of writing the Act is not yet in force.

Modern life requires a household to share certain activities and responsibilities in order to keep going; obvious ones are cooking, cleaning, shopping, home maintenance, paying bills and budgeting. Daily living requires personal activities, such as attending to personal hygiene, dressing, feeding, drinking and toileting.

As MND progresses many of the previously shared activities are taken on by the healthy partner, who often assumes additional responsibility for their partner's personal activities as debility increases. The purpose of the carer's assessment is to ensure that the carer is able to cope with these extra duties and doesn't become worn out by all this extra activity. The carer's assessment should also identify opportunities for respite care and ways to share the care amongst others to allow the main carer time to recharge their batteries. In some circumstances this help can be in the form of a "Home Care package," provided jointly by the local Social Work department and the local Health Board. If you have a carer's assessment and your council offers you support in your caring role, it can't charge you for it. If support is given to the person you're caring for after an assessment of their care needs, they may be charged separately for this help. Our Welfare and Benefits officers will advise you on this

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and ensure that you receive any benefits to which you are entitled.

See Factsheet 4, "Benefits in Brief," for a quick summary of some possible entitlements. The [Care Information Scotland](#) website also provides very clear information on this topic.

Although younger people do suffer from MND the majority of people with the condition are older and will have been together for many years. As such they will have adapted their lives to accommodate each other's likes and dislikes and, as MND sets in, they will naturally adapt, the healthier partner understanding subtle cues and working on information gleaned from years of living with their partner. Someone else, such as a mature child, cannot ever know their parents in the same way as the parents know each other and might not be as trusted a carer or, in the mind of the person with MND, as effective a carer as their partner. (For anyone with MND reading this factsheet, think about it, is anyone as good as your spouse?)

**It is important that others should become involved at an early stage in the disease in order that their learning and knowledge can develop along with those of the principal carer.**

It is only natural that the person who cares for you most and knows you best should be the one that you rely on most to understand your daily routines, your subtle signs and other needs.

It is, therefore, important for the principal carer that others should become involved at an early stage in the disease in order that their learning and knowledge can develop along with those of the principal

carer in order to avoid over-reliance on one person only.

The obvious way to avoid this possibility is to actively plan to share the responsibilities with others and to accept help. The older you are the more important this becomes as being a full time carer can have detrimental effects on the health of the carer. In the survey mentioned earlier 12%, i.e. one in eight, of all carers, reported that their health had suffered as a result of being a carer. Sometimes this resulted in hospitalisation of the carer with consequent changes to the arrangements for the person they cared for.

There is always someone who can take over from you, they may not be as knowledgeable or as experienced, but they will learn once you are not there. Would it not be better to be there to both teach them and learn from them on how to share the responsibilities?

Carer "burn-out" is not uncommon and can only be guarded against by making sure that you have adequate time off from caring to attend to your own needs.

Sharing the care will reduce the chances of you being over-burdened and give you a chance to recharge your own batteries for the remainder of the week. It is most important that carers put their own health first, despite their natural tendencies to put their caring duties first.

Why do you think the safety briefing before an airline flight insists that in an emergency you should put your own oxygen mask on first before helping others? Obviously, if you have a supply of oxygen it will allow you to help others, while you can still breathe easily. If you attend to fastening an oxygen mask to everyone around you first you might lose

consciousness yourself before you have fitted the first one, then who will provide everyone with help?

**Why do you think the safety briefing before an airline flight insists that in an emergency you should put your own oxygen mask on first before helping others?**

The demands on a carer are exactly like that, it is too easy to get caught up in what you are doing to the detriment of your own health. You must make sure of your own health first in order that you can be more effective for those around you and sometimes that means that you need to agree with your partner that you do need time to revitalise yourself when others will take over.

### **Sources of Help and Support**

Practical help can come from a number of different sources. Family and friends are often the first ones to rally round.

Someone cooking a couple of meals for you all each week, someone else taking responsibility for your laundry or light housework and so on can all help take little bits of pressure off you as the principal carer.

There are also professional and voluntary organisations that can help with caring matters. Your local social work department will have some kind of "Home Care" service intended to help keep people at home and out of hospital. The exact services provided by different local home care services vary across the country and in some cases your social work department may buy-in these services on your behalf from private agencies. To find out more about the types of home care support offered by

your local authority ask any of the health professionals who are currently helping you, or contact your local social work department office directly. A list of Local Council headquarters is available to download from the MND Scotland website. Their telephone operators should be able to put you in touch with the appropriate local officers to help you.

### **Direct Payments**

It is also possible to ask for the money your council might spend on home care to be paid to you directly (It is called "Direct Payment") in order that you can buy in the care you need if what the council offers does not match exactly with your needs. You need to be careful if you choose to go down this route. Unless the person you pay is declared to be self employed, or you buy their services from an agency, you will be deemed to be their employer. If they are not self employed and you pay them for their services you will need to meet the wide variety of legal requirements that are placed on employers. Again your social work department should know of the services available in your area.

Carers Scotland provides a well maintained web-page on direct payments; see "Sources of Support and Further Information" at the end of this factsheet for contact details.

Other organisations, such as Crossroads Scotland, provide a network of care attendants to enable carers to take a break. Local Crossroads groups can provide breaks, holiday and respite care. Exactly which services are available in your area depends on how your local Crossroads group is organised and funded.

### **Respite and Care**

In the latter stages of MND nursing help can sometimes be obtained from the Marie Curie organisation, which has recently widened the types of illness it will deal with. Until recently Marie Curie would only deal with patients suffering from malignant illness, but a recent change in policy has widened their services to include neurological conditions.

Support for carers themselves can be provided by the Carers Trust which has a network of carers' centres across the country, sometimes working from local social work department premises. Activities vary according to the needs and likes of the local membership. One important function of these centres is that they bring current and former carers together in a supportive environment where a lot of valuable knowledge and tips can be exchanged.

**The experience and expertise brought by the hospice movement is an invaluable tool in the armoury of a carer.**

Respite care, day hospice or day care is sometimes available through local hospices or hospitals. The common view is hospices are places where living

people go to die, whereas those working in the hospice environment often see them as places where dying people go to live, the emphasis being upon treating people as individuals and addressing their specific needs to improve their quality of life.

The experience and expertise brought by the hospice movement is an invaluable tool in the armoury of a carer for someone with MND. Not only can it bring comfort to the person with MND it can also provide reassurance and breathing space for a carer.

In the theatre there are understudies for major roles in any production so that if any of the stars of the show go down with some illness there is someone in the wings who knows the role and can step in at short notice. This kind of planning makes even more sense when someone else's life depends on you staying healthy.

If you require more help or information with issues related to being a carer please contact any of the organisations listed below, if your query is specifically related to MND please contact MND Scotland on 0141 332 3903, we will be only too happy to help if we can.

### **Sources of Support and Further Information**

**Care Information Scotland** <http://www.careinfoscotland.scot/topics/support-for-carers/>

**Carers Scotland**, website [www.carersuk.org/scotland](http://www.carersuk.org/scotland)

**CarersLine** (Wed & Thur, 10am-Noon and 2pm -4pm) 0808 808 7777

**Carers Trust** [www.carers.org](http://www.carers.org) Tel 0300 123 2008 or email [scotland@carers.org](mailto:scotland@carers.org)

**Crossroads Scotland**, 0141 226 3793 [www.crossroads-scotland.co.uk](http://www.crossroads-scotland.co.uk) offers respite care

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**Citizens Advice** [www.cas.org.uk](http://www.cas.org.uk)

**Information on Carers Allowance** [www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance)

**Disability Living Foundation**, Tel 0845 130 9177 [www.dlf.org.uk](http://www.dlf.org.uk)

**Independent Age**, Tel 0800 319 6789 [www.independentage.org.uk](http://www.independentage.org.uk) can offer limited financial support.

**The Silverline for Older People** (Helpline) 0800 4 70 80 90  
[www.thesilverline.org.uk](http://www.thesilverline.org.uk) A confidential, free helpline for older people across the UK

**Living Made Easy**, advice on available aids and products [www.livingmadeeasy.org.uk/](http://www.livingmadeeasy.org.uk/)

### Booklets and Factsheets;

As well as being available to download from the Carers UK and Carers Scotland websites, each of these is available to borrow from the MND Scotland Library.

**'Carers Rights Guide 2016 – Looking after Someone'** <http://www.carersuk.org/help-and-advice/get-resources/carers-rights-guide>

**A guide to carers' rights and benefits** [www.carersuk.org/help-and-advice/financial-support/help-with-benefits](http://www.carersuk.org/help-and-advice/financial-support/help-with-benefits)

[CarersUK factsheets](#) cover assorted topics relevant to carers.

### MND Scotland Factsheets

Factsheet 4	Benefits in Brief
Factsheet 5A	Assistive Equipment
Factsheet 5B	Maintaining Mobility
Factsheet 5C	Getting the Best From Physiotherapy
Factsheet 5D	Maintaining Mobility
Factsheet 8	Care Planning & End of Life Issues
Factsheet 14	Making A Legacy
Factsheet 24	Powers of Attorney
Factsheet 25	Guardianship and Intervention Orders
Factsheet 33	Managing MND
Factsheet 40	Ventilation in MND

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