



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 official statistics just under 480,000 people in Scotland are carers, i.e. almost one in ten of the population and includes children looking after siblings and parents. Just under half of this number is not in full time work while two-fifths are in full time work. The remainder are in various forms of part time work.

In a 2006 report Carers UK found that 65% of people with a caring role did not identify themselves as carers in the first year of caring and that it took longer than five years before the last 1/3<sup>rd</sup> of the group began to identify themselves as carers.

Although 50% of those who replied to the survey did not feel they had missed out on state benefits, 29% of those who replied had missed out on benefits they were entitled to for over three years, while 34% had missed out on practical support for three years or longer. Unfortunately, state benefits are not backdated beyond the date of claiming them and on average those carers who did not claim Carer's Allowance each lost out on over £2,400 of

income per year, (more than £2,600 at 2008/9 rates.)

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."*

**MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.**

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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

Local authorities are to ensure carers are made aware of this right and are also required to take account of the contribution of carers, and 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.

The 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 decides what package of care to provide to the cared-for person.

Support packages from local authorities and the NHS should, theoretically, be seamless now that local delivery of Social

Work and NHS Community services are grouped under the umbrella heading of “Community Health Partnerships.” In addition to these services there may be other entitlements to benefits both to pay for these services and entitlement to benefits because of other circumstances. See Factsheet 4, “Benefits in Brief,” for a quick summary of some possible entitlements.

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.

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?

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.

**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?**

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 Princess Royal Trust for Carers, 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

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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 945 1077, we will be only too happy to help if we can.

### Sources of Support and Further Information

**Carers Information and Support Line 0141 353 6504**

[www.crossroads-scotland.co.uk/cislmain.htm](http://www.crossroads-scotland.co.uk/cislmain.htm)

**Carers Scotland**, 91 Mitchell Street, Glasgow, G1 3LN. tel: 0141 221 9141. e-mail [info@carerscotland.org](mailto:info@carerscotland.org) website [www.carerscotland.org](http://www.carerscotland.org)

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

**Princess Royal Trust for Carers** [www.carers.org](http://www.carers.org) Tel 0141 221 5066

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

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

**“Directgov” Information for Carers** [www.direct.gov.uk/carers](http://www.direct.gov.uk/carers)

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

The information in this leaflet is believed to be accurate at the time of production, MND Scotland cannot give detailed medical advice, this leaflet should be regarded only as general background information.

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**Independent Age**, Tel 020 7605 4200 [www.independentage.org.uk](http://www.independentage.org.uk) can offer limited financial support.

**Scottish Helpline for Older People**, 0845 125 9732 offers advice on benefits

### Booklets and Factsheets;

As well as being available to download from the Carers Scotland website each of these is available to borrow from the MND Scotland Library at Firhill Road

“**New to Caring**,” information for people who provide unpaid care.

[www.carerscotland.org/Information/Newtocaring](http://www.carerscotland.org/Information/Newtocaring)

“**Looking After Someone, a guide to carers’ rights and benefits 2008/2009.**”

[www.carersuk.org/Newsandcampaigns/CarersRightsDay/Adviceguidesforcarers](http://www.carersuk.org/Newsandcampaigns/CarersRightsDay/Adviceguidesforcarers)

“**Finding the balance, Promoting positive health.**” A short booklet on looking after yourself as a carer.

[www.carerscotland.org/Information/Takingcareofyourself/NewHealthResourceGuideforCarers](http://www.carerscotland.org/Information/Takingcareofyourself/NewHealthResourceGuideforCarers)

“**An Employees Guide to Work and Caring**,”

[www.carerscotland.org/Information/Workandcaring/Flexibleworking](http://www.carerscotland.org/Information/Workandcaring/Flexibleworking)

“**Support for Carers: A Guide to Telecare**,” A guide to remote monitoring aids that can help give you peace of mind when away from home.

[www.carerscotland.org/Information/Telecaresupportingcarers](http://www.carerscotland.org/Information/Telecaresupportingcarers)

“**Benefits for Carers**,” is a factsheet available to borrow, although it is not downloadable more detailed information on benefits carers might be entitled to is available from

[www.carerscotland.org/Information/Financialhelp](http://www.carerscotland.org/Information/Financialhelp)

“**Direct Payments**” information for carers is available to read and download at:

[www.carerscotland.org/Policyandpractice/Keylegislationandpolicy/SelfDirectedCareDirectPayments](http://www.carerscotland.org/Policyandpractice/Keylegislationandpolicy/SelfDirectedCareDirectPayments)

The reports “**The Importance of Information for carers**” and “**Whose rights are they anyway? Carers and the Human Rights Act**,” appear not to be available to download at the time of writing, but can be borrowed from the MND Scotland Library.

**Help the Hospices** produce (and issue updated supplements to) a manual called “**Caring for Carers**” which is both available to borrow in hard copy from MND Scotland or can be downloaded from the following link. The title is deliberately ambiguous as the content covers both care of the carer and care given by the carer. Sections include “Money Matters,” “Caring at Home,” “Nursing Information,” and “Death and Dying” amongst others.

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If you find it useful, sections of the manual can be copied for you for inclusion within your MND Scotland Patient Information Folder.

[www.helpthehospices.org.uk/our-services/developing-practice/carers/publications/carers-pack/](http://www.helpthehospices.org.uk/our-services/developing-practice/carers/publications/carers-pack/)

### 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