
MND Scotland Patient Information Folder Introduction and Acknowledgements

Isaac Newton once claimed that his insight into the world of physics, and gravity in particular, was possible only because he had “stood on the shoulders of giants.” With a nod to similar sentiments MND Scotland would like to acknowledge the ALS Society of Canada and the MND Association of England Wales and Northern Ireland as the originators of many of the resources that have been adapted to provide these factsheets.

Both the MND Association and the ALS Society of Canada have produced comprehensive manuals describing many aspects of concern to the wider community of MND patients and their families. If required these can be downloaded from their respective websites at www.als.ca and www.mndassociation.org.

Due to the variability of MND we felt it was unnecessary to present all of the possibilities posed by the disease to the newly diagnosed and chose to divide the subject into a series of factsheets guided by the Canadian manual but contextualised for Scotland, Scots law and the Scottish social and health care systems. These factsheets have been further grouped into a number of subdivisions that we consider to be appropriate to particular stages of the disease (see page iv.)

A patient information folder in which to file the factsheets is available free to those living in Scotland with a diagnosis of MND. The folder is supplied with this introduction, a feedback questionnaire and the following factsheets; 1 *What is*

MND? 20 Library and Information Service, 23 Tools to Help You, 31 Sources of Support, 32 MND Scotland.

Additional factsheets can be downloaded from the MND Scotland website or can be supplied in hard copy by post. Either contact our information officer to request the copies you require on 0141 945 1077 or download them yourself from our website.

(www.mndscotland.org.uk/information)

The introductory factsheets describe the condition; suggest ways of coping with the disease and sources of support for both those with the disease and their families. More advanced groups of factsheets deal with specific aspects of the disease such as motoring and travel, ways to cope with and to manage physical disability, what is happening in research and drug developments, issues related to communications, breathing and feeding if these aspects become relevant and a group defined as “Advanced and Legal Issues” which are concerned with factors necessary for advanced planning, for end-of life and bereavement.

Not everyone will want to read every factsheet in every group, and some may shy away from reading some of those contained in certain groups. For this reason we have provided advanced warning of the likely contents both by the group names and by the titles of the factsheets themselves. There is no significance or logic to the factsheet numbers themselves apart from their value to the writers in keeping track of the various documents as they evolved and their titles changed.

MND Scotland is the working name of The Scottish Motor Neurone Disease Association and is the only charity registered and working in Scotland for the relief of Motor Neurone Disease. Scottish Charity number SC002662

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Introduction and Acknowledgements

Of necessity some of the factsheets' contents are much more complex than some people will be willing to tackle. Unfortunately this is the nature of modern medicine, particularly medical genetics which seems to be increasingly relevant to an ever increasing number of conditions.

Thanks should go to the writing team at MND Scotland for their contributions to the development of the factsheets, to the many copyright holders who gave permission to include their photographs, to Jane Wood of Dundee for the original medical illustrations and to Wikimedia for their copyright free diagrams that are used to illustrate many of the more scientific factsheets.

For those unfamiliar with the internet it is worth pointing out that when any of the factsheets or supporting documents are viewed on-screen with an internet connection any embedded links such as www.mndscotland.org.uk are "live" and will take you to the website, open the document to which they refer or, if an email address, prepare and address a blank e-mail to the recipient if clicked with the left button of your mouse or touchpad.

Due to limitations of technology used to produce the downloadable versions this automatic linking does not always work when the URL or e-mail address scrolls onto a second line. For these you will have to cut and paste the details of the link into the appropriate e-mail client or web-browser.

Available Factsheets

Number	Title	Number	Title
1	What is Motor Neurone Disease?	23	Tools to help You
1B	What is MND? – More Detailed	24	Powers of Attorney
2	Inherited MND	25	Guardianship and Intervention Orders
3	Introducing Genetics	26	Current Research
3B	Disease Inheritance	27	Coping with MND
4	Benefits in Brief	28	Complementary Therapies
5A	Assistive Equipment	29	Telling Children About MND
5B	Maintaining Mobility	30	Communication Strategies
5C	Getting the Best from Physiotherapy	31	Sources of Support
5D	Aids to Maintain Mobility	32	MND Scotland
6	Feeding Tubes	33	Managing MND
7	Bereavement and Children	34	Adapting to Swallowing Problems
8	Care Planning and End-of-Life Issues	35	Breathing Matters
9	Travelling and Holidays	36	Oral Health
10	Creatine	37	Long Distance Travel
11	Vitamins and MND	38	Financial and Legal Issues
12	Travel Insurance	39	Lithium
13	Coping after Bereavement	40	Ventilation in MND
14	Making a Will and Leaving Legacies	41	
15	Palliative Care	42	Being a Carer
15A	Care at Home	43	Useful Organisations
16	Stem Cells	44	Advance Directives
17	Motoring and MND	45	After a Bereavement
18	Clinical Trials	46	Bereavement Benefits
19	Sex and Sexuality	47	Recommended Reading
20	Library and Information Service	48	Medical Bequests
21	Specialist Clothing	49	Managing Your Money
22	Riluzole		Sheriff Court Contact Details
			Appendix 2: Sample Powers of Attorney
			Local Authority Contact Details

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Factsheet Groupings

<p style="text-align: center;">Introductory</p> <p>1 What is MND? 1B What is MND More Detailed 2 Inherited MND 3 Introducing Genetics 15A Care at Home 20 Library and Information 23 Tools to Help You 27 Coping with MND 29 Telling Children About MND 31 Sources of Support 32 MND Scotland 42 Being a Carer 43 Useful Organisations 47 Recommended Reading</p>	<p style="text-align: center;">Physical Disability</p> <p>5A Assistive Equipment 5B Maintaining Mobility 5C Getting the Best From Physiotherapy 5D Aids to Maintain Mobility 19 Sex and Sexuality (in development) 21 Specialist Clothing 33 Managing MND</p>	<p style="text-align: center;">Communications and Feeding</p> <p>6 Feeding Tubes 30 Communication Strategies 34 Adapting to Swallowing Problems 35 Breathing Matters 36 Oral Health</p>
	<p style="text-align: center;">Spare Numbers</p> <p>41 No title Allocated</p>	<p style="text-align: center;">Motoring & Travel</p> <p>9 Travelling and Holidays 12 Travel Insurance 17 Motoring and MND 37 Long Distance Travel</p>
<p style="text-align: center;">Money Issues</p> <p>4 Benefits in Brief 38 Financial and Legal Issues 46 Bereavement Benefits 49 Managing Your Money (in development)</p>	<p style="text-align: center;">Research, Drugs and Trials</p> <p>3B Disease Inheritance 10 Creatine 11 Vitamins and MND 16 Stem Cells 18 Clinical Trials 22 Riluzole 26 Current Research</p> <p>28 Complementary Therapies 39 Lithium</p>	<p style="text-align: center;">Advanced and Legal Issues</p> <p>7 Bereavement and Children 8 Care Planning and End of Life Issues 13 Coping after Bereavement 15 Palliative Care 14 Leaving a Legacy 24 Powers of Attorney 25 Guardianship and Intervention Orders 40 Ventilation in MND 44 Advance Directives 45 After a Bereavement 48 Medical Bequests</p>

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Factsheet Feedback Questionnaire

Please take a few minutes to give us feedback on how useful, or otherwise, you found the factsheets you have read or used. There is a reply paid envelope included in the front pocket of the Patient Information Folder to return this questionnaire. If there are other issues on which you would like us to develop factsheets please let us know by completing the section overleaf.

Replies can be anonymous, but if you do give us your name and contact details we can keep you up to date with revisions to the factsheets as these take place

I have these	Number	Title	Useful	Neither one or other	Not useful at all
X	1	What is Motor Neurone Disease?			
	1B	What is MND? – More Detailed			
	2	Inherited MND			
	3	Introducing Genetics			
	3B	Disease Inheritance			
	4	Benefits in Brief			
	5A	Assistive Equipment			
	5B	Maintaining Mobility			
	5C	Getting the Best from Physiotherapy			
	5D	Aids to Maintain Mobility			
	6	Feeding Tubes			
	7	Bereavement and Children			
	8	Care Planning and End-of-Life Issues			
	9	Travelling and Holidays			
	10	Creatine			
	11	Vitamins and MND			
	12	Travel Insurance			
	13	Coping after Bereavement			
	14	Making a Legacy			
	15	Palliative Care			
	15A	Care at Home			
	16	Stem Cells			
	17	Motoring and MND			
	18	Clinical Trials			
	19	Sex and Sexuality			
X	20	Library and Information Service			
	21	Specialist Clothing			
	22	Riluzole			
X	23	Tools to help You			
	24	Powers of Attorney			
	25	Guardianship and Intervention Orders			
	26	Current Research			
	27	Coping with MND			
	28	Complementary Therapies			
	29	Telling Children About MND			
	30	Communication Strategies			
X	31	Sources of Support			

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Factsheet Feedback Questionnaire

I have these	Number	Title	Useful	Neither one or other	Not useful at all
X	32	MND Scotland			
	33	Managing MND			
	34	Adapting to Swallowing Problems			
	35	Breathing Matters			
	36	Oral Health			
	37	Long Distance Travel			
	38	Financial and Legal Issues			
	39	Lithium			
	40	Ventilation in MND			
	42	Being a Carer			
	43	Useful Organisations			
	44	Advance Directives			
	45	After a Bereavement			
	46	Bereavement Benefits			
	47	Recommended Reading			
	48	Medical Bequests			
	49	Managing Your Money			

Please use the space below to make any comments regarding the factsheets you have used or would like to see developed. If your comments don't fit in the space please feel free to use a continuation sheet.

Name:	I am already a member of MND Scotland. <input type="checkbox"/> Yes <input type="checkbox"/> No
Address:	I would like free membership of MND Scotland. <input type="checkbox"/> Yes <input type="checkbox"/> No
e-mail address	
Comments	

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