



Caring and MND: support for you

The development of an
award winning guide

Background

Who cares for the carer?

- our Carer Strategy
- equality of provision
- new guide to help carers look after their own wellbeing
- funding



time for
me

Goal



Why?

Joe

- diagnosed 2008 at 56 years of age
 - married with two children
 - took early retirement (not wanted)
 - began reviewing resources 2010
 - joined user review group early 2011
 - always first to respond
-
- responded 5.30pm, on a Friday in July 2011
 - died 7pm, the same Friday, aged 59 years

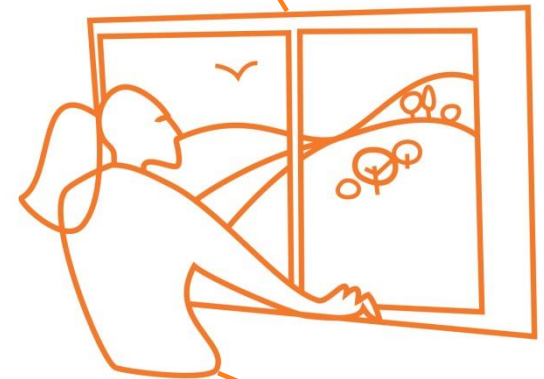


Sarah

- ex-carer, joined user review group 2011
- husband had MND – died 2008
- keen to help carers and young carers
- three children
- helped test first edition of carer guide 2011

- excellent reviews on batch 1 and batch 2

- withdrew during batch 3 due to impact of content



Why revise?

- due for review in revision cycle
- original format too heavy
- health literacy – Plain English
- simplification to reduce repetition
- updates, eg Care Act



**Complete overhaul for presentation, content and scope.
Redevelopment rather than revision.**

Need?

“Advice about looking after yourself, taking breaks and so on, is the most difficult to follow. It’s perfectly sound – we understand the good sense employed – just impossible to accomplish.”



“I needed someone in authority to tell me that after seven and a half years of caring and not sleeping properly, it was okay to take a break.”

“I have had to learn to give myself permission to be good to me.”

Evidence

- articles, studies, research
- The Care Act
- other legislation
(England, Wales and Northern Ireland)
- GOV.UK
- 8 focus groups across UK 2009
- Carers' surveys 2011 and 2015
- Improving MND Care survey 2013
- feedback from existing guide
- interviews and personal stories



Includes?

- acceptance and adjustment
- rights and carers' assessments
- support
- emotions and wellbeing
- young carers
- beyond the caring role
- our services
- list of useful organisations



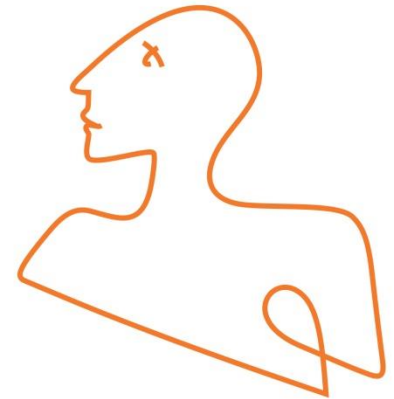
Ease of use?

- professional design following tender
- colour to highlight sections, headings, quotes
- page borders
- cross referencing
- further information
- readability – short sentences, simple terminology
- web versions, interactive and separate sections
- summary quick guide



Review

- internal verification
- user review group (6 carers and ex-carers)
- panel of 6 health and social care experts
 - ✓ academic (Institute of Public Care, Oxford Brookes)
 - ✓ specialist nurse and MND care centre co-ordinator
 - ✓ community nurse
 - ✓ clinical psychologist
 - ✓ information specialist: Carers Northern Ireland
 - ✓ commissioning manager (carers lead)



Impact?

“This information is so useful. I think that sometimes people take on a caring role, but don’t realise they are carers and don’t get the help that is available to them.”

Carer supporting a person with MND



“I would like to share this information with my providers, as I think it is an excellent template to help carers, whoever they are caring for.”

**Sonja Woodhouse, Commissioning Manager Carers Lead,
Northamptonshire County Council**

“Who cares for the carer? What a great resource from @mndassoc Recognise so many of the quotes. Lots to help here.”

Carer supporting a person with Kennedy’s disease

Impact?

First 9 months 1275 hardcopies ordered

Downloads: 201

Most popular individual section: What to expect



Compared to:

327 hardcopies 2015 for previous version

Not available online.

Accreditation



**Health & care
information
you can trust**

The Information Standard



**Certified
Member**

Award

Patient Information Resource of the Year 2016 The British Medical Association – BMA Awards



Key points

- ✓ process
- ✓ evidence
- ✓ stakeholders
- ✓ user test
- ✓ expert review
- ✓ promote
- ✓ evaluate and revise

A publication is never finished unless it becomes obsolete.

Joe and Sarah

