Second Report of Session 2014-15

Managing the care of people with long-term conditions

Volume II
<http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/401/401vw.pdf>
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Written evidence from Action for M.E. (LTC 40)
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Executive Executive Summary
- Focusing on four terms of reference from the Health Select
Committee's inquiry, this submission is based on responses to a short
survey by 252 people with the fluctuating long-term condition, Myalgic
Encephalomyelitis (M.E.).
- Most respondents (72.1%) have co-morbid conditions and 39% agreed
that their healthcare professional sees them just as a collection of
symptoms to be treated.
- 60.9% said their healthcare professional is not aware of their
social care needs and 54% said their
healthcare and social care are not joined up at all. Specific examples
are given.
- Around 90% have been seen by more than one healthcare professional
for their M.E., and 54.2% agreed that they complemented each other in
delivering patient care.
- Many respondents spoke of the anxiety, depression and isolation that
comes from living with a longterm, fluctuating condition that is still
little understood. Less than half said their mental health issue was
considered separately from their M.E. by their healthcare professional.
- 87% said they didn't have a care plan based on their individual
needs and 37.7% said their healthcare professional valued their ideas
when it came to working out treatment. Specific examples are given.

1. Background

1.1 Myalgic Encephalomyelitis (M.E.) is a fluctuating long-term
condition that affects around 250,000 men, women and children in the
UK. It causes symptoms affecting many body systems, more commonly the
nervous and immune systems. Around 25% of patients are severely
affected, and may be confined to bed or unable to leave the house
without the use of a wheelchair.

1.2 Action for M.E. is the UK's largest charity for people affected by
M.E. We provide information and support, campaign for better services
and more effective treatments, and drive and invest in research.

1.3 Our submission focuses on four terms of reference from the Health
Select Committee's inquiry into the management of long-term
conditions.inquiry into the Management of long-term conditions inquiry
into the Management of long-term conditions It is based on responses
to a 14-question survey for people with M.E. in England, devised by
Action for M.E. and publicised via our Online M.E. Centre191 and
social media sites192 from 4 to 30 April 2013.

1.4 The survey was answered by 252 people with M.E. This was a good
response given the short time frame. Results of the survey reflect
what we expected and are broadly representative of people with M.E.,
with who the charity is in daily contact.

1.5 The duration of respondents' illness is as follows:
(250 respondents answered this % of respondents Number of
question) respondents
Had M.E. for less than one year 2.8 7
Had M.E. for up to two years 8.4 21
Had M.E. for up to five years 18.8 47
Had M.E. for up to ten years 22.4 56
Had M.E. for more than ten years 47.6 119

2. This Section Refers to the Ability of NHS and Social Care Providers
to Treat Multi-Morbidities and the Patient as a Person Rather than
Focusing on Individual Conditions.

2.1 Of the 244 people who answered the question 'Do you have any other
conditions?'
- 27.9% (68 respondents) said no.
- 72.1% (176 respondents) said yes.

2.2 These conditions most commonly include fibromyalgia, anxiety,
depression, asthma, irritable bowel syndrome and thyroid-related
conditions.

2.3 Respondents were asked to tick all the statements that applied to
them. Responses were as follows:
(209 respondents answered this % of respondents Number of
question) respondents
I have to attend different 49.8 104
appointments to have check-ups
for different conditions
My healthcare professional 36.8 77
considers each of my conditions
separately
I can make one appointment to 55.5 116
discuss symptoms for any number
of my conditions with my healthcare
professional

2.4 A respondent in Buckinghamshire said: 'Some of my GPs are often
biased by the diagnosis of M.E. when I try and discuss another issue
or want to seek further advice or tests. It can also take some time to
discuss a condition properly in light of other conditions I have,
which can be difficult in a 10 minute slot.'

2.5 Action for M.E. supports the view that a holistic approach,
encouraging patients to discuss more than one symptom and condition,
in each appointment, would be helpful. We appreciate that GPs must
operate within strict time constraints, so it would be helpful if
patients with M.E. and other long-term conditions could be encouraged
to book double appointments.

2.6 Respondents were asked to tick all the statements that applied to
them. Responses were as follows:
(231 respondents answered this % of respondents Number of
question) respondents
My healthcare professional 61 141
treats me as a person, not just
as an illness or illnesses
My healthcare professional sees 39 90
me just as a collection of
symptoms to be treated

2.7 Action for M.E. was pleased to see that a majority of patients
agreed that their healthcare professional treats them as a person, not
just as an illness or illnesses. However, the Aviva health of the
nation index found that M.E./CFS was the condition that GPs find most
challenging to refer for specialist attention, and has been so for the
last ten years.193

2.8 We believe awareness and understanding for patients could be
improved if GPs were able to access better education about M.E.
Charities such as Action for M.E. and local M.E. support groups could
help facilitate this.

2.9 Respondents were asked to tick all the statements that applied to
them. Responses were as follows:
(235 respondents answered this % of respondents Number of
question) respondents
My healthcare professional is 60.9 143
not aware of my social care needs
My healthcare professional is 17.9 42
aware of my social care needs
and takes them into account
My healthcare and my social care 54 127
are not joined up at all
My healthcare and my social care 5.1 12
are reasonably well-integrated
My healthcare and my social care 0.4 1
are very well-integrated

3. This Section looks at Examples of Effective Integration of Services
across Health, Social Care and other Services which Treat and Manage
Long-Term Conditions.

3.1 We asked respondents to indicate which healthcare professionals
they have been treated by for their M.E.
(241 respondents answered this % of respondents Number of
question) respondents
Consultant specialising in M.E. 59.8 144
Consultant not specialising in 36.1 87
M.E.
Physiotherapist 31.1 75
Occupational therapist 38.6 93
Psychologist or counsellor 32.8 79
Other (most common answers: 29.9 72
alternative and private
practitioners)

3.2 Around 90% of respondents (221 out of 241) had been seen by more
than one healthcare professional for their M.E. We asked if these
healthcare professionals complemented each other in delivering their
care. Of the 227 people who answered this question:
- 54.2% (123 respondents) said yes.
- 17.6% (40 respondents) said no.
- 29.5% (67 respondents) said they weren't sure.

3.3 We asked respondents to tell us more about their experience of
this if they could, and 125 did so. Examples include:

3.4 'I had to keep repeating myself every time I saw somebody
different, even if they were members of the same team, which was
exhausting for someone with M.E.' (Respondent in Yorkshire)

3.5 'I access all the people via the CFS/M.E. North East service
(based in Newcastle) which I was referred to via my GP. The service
updates my GP well so he can offer advice mid sessions.' (Respondent
in Northumberland)

3.6 'Bristol has a wonderful M.E. centre at Frenchay Hospital where
there is multi-disciplinary care from medics, OTs, physiotherapists,
psychologists etc. My GP (both now and where I lived before)
acknowledged both that I am an expert patient when it comes to this
and the superiority of the knowledge of the M.E. team, and so will go
along with what they suggest.' (Respondent in North Somerset)

3.7 'The consultant copied letters to me to my GP. She referred me to
a psychologist who was trained in offering CBT for M.E. patients and
knew a lot about M.E. Again, he copied his assessment to my GP. I've
also seen a psychologist for depression, referred to by my GP, and she
also copied assessments to my GP.' (Respondent in Oxfordshire)

3.8 We asked respondents what social care services they had been
offered in the last year.
(240 respondents answered this % of respondents Number of
question) respondents
none 80.8 194
day-time carer assisting with 4.2 10
personal care
day-time carer assisting with 3.8 9
non-personal care
night-time carer 0.4 1
Adaptations in the home 11.3 27
Telehealth and telecare services 2.1 5

3.9 A respondent in Suffolk told us: 'After contacting Social Services
in October 2012, I am still waiting for an appointment to discuss what
care I am entitled to. Three out of five appointments have been
cancelled within 48 hours of the scheduled appointment, by the social
worker.'

3.10 Many respondents told us they rely on their immediate family for care.

3.11 We asked if respondents if social care professionals working with
them complemented each other in delivering their care. Of the 83
people who answered this question:
- 67.5% (56 respondents) said no.
- 6% (5 respondents) said yes.
- 30.1% (28 respondents) said they weren't sure.

3.12 We asked respondents to tell us more about their experience of
this if they could, and 32 did so. None were able to offer examples of
effective integration of services.

3.13 A respondent in Ipswich told us: 'I have been advised by my
social worker that they cannot and will not get involved with any care
relating to my children and therefore any care provided for me is for
me and me alone. This is particularly unhelpful, especially as I am no
closer to getting a care package in place for me after making first
contact with social services more than six months ago.'

3.14 A majority of people with M.E. (86%-see paragraph 3.6) told us
they have been offered no social care services in the last year. Given
the disabling physical symptoms of M.E., and the fact that 25% of
patients are severely affected (house- or bed-bound), we believe it is
important to have a national approach to improving quality and
developing social care, with specific guidance for specialist
conditions such as M.E.

4. This Section refers to the Interaction between Mental Health
Conditions and Long-Term Physical Health Conditions.

4.1 Living with a long-term condition such as M.E. is no easy task.
Some people with M.E. find themselves facing a mental health issue,
such as depression or anxiety, as a result. We asked respondents to
tell us about their experience of this, and 217 did so.

4.2 Many respondents spoke of the anxiety, depression and isolation
that comes from living with a longterm, fluctuating condition that is
still little understood. Some felt that their GP understood this
reaction, while others are wary of discussing mental health issues
alongside their M.E.

4.3 A respondent in Greater Manchester said: 'I fear saying anything
because my GP and healthcare professionals have so many times tried to
attribute any symptoms I have down entirely to me being depressed.'

4.4 We asked respondents if their mental health issue was considered
separately from their M.E. by their healthcare professional. Of the
213 people who answered this question, 23.8% (50 respondents) said
this question wasn't relevant to them. Of the remaining 163 respondents,
- 43.6% (71 respondents) said yes.
- 35% (57 respondents) said no.
- 21.4% (35 respondents) said they weren't sure.

4.5 We asked respondents to tell us more about their experience of
this if they could, and 105 did so.

4.6 A respondent in West Sussex said: 'Sometimes I have felt that
healthcare professionals consider my health issues and physical
symptoms to be caused by depression or anxiety, which I find extremely
frustrating as I feel my anxiety and depression are brought on by the
M.E. and not the other way around.'

4.7 M.E. is a neurological condition, not a mental health problem.
While it is encouraging to see that 43.6% (see paragraph 4.4.)
reported that their mental health issue was considered separately from
their M.E. by their healthcare professional, just over a third did
not, while more than a fifth said they weren't sure, indicating a lack
of clarity in communication from their healthcare professional.
Understanding and awareness of M.E. among health professionals must be
improved.

5. This Section refers to the Extent to which Patients are being
offered Personalised Services, and Patient Contribution to better
Outcomes.

5.1 We asked respondents if they have a care plan based on their
individual needs. Of the 230 people who answered this question:
- 87% (200 respondents) said no.
- 7.8% (18 respondents) said yes.
- 5.2% (12 respondents) said they didn't know.

5.2 We asked respondents to tell us more about their experience of
this if they could, and 57 did so.

5.3 One respondent in Greater Manchester said: 'Since moving to my
current address five months ago I have found it very frustrating that
my care support plan has not been adhered to. I have received mostly
help with domestic tasks and no personal care. It has not addressed my
individual needs and has also been too expensive for me to afford,
meaning that I have had to cancel care and am now making a formal
complaint.'

5.4 We asked respondents if they thought that their healthcare
professional valued their ideas when it came to working out treatment.
Of the 223 people who answered this question:
- 37.7% (84 respondents) said yes.
- 34.5% (77 respondents) said no.
- 30.9% (69 respondents) said they weren't sure.

5.5 We asked respondents to tell us more about their experience of
this if they could, and 120 did so. Some examples of effective patient
contribution to better outcomes include:

5.6 A respondent in Kent said: 'The fluctuations and limitations of my
illness (dysphonia/sensory sensitivity) make consultations either
difficult to attend or very long (always double appointments). So
about a year ago my GP provided me with his surgery email address so
that I can provide him with updates and relevant research material
prior to consultation to inform my on-going care. As a result his
knowledge of my illness and support for me has increased and my
consultations with him are more constructive.'

5.7 Listening to patients as individuals, as well as through national
bodies such as Healthwatch England, is key to better patient outcomes.
Action for M.E. is encouraged to see that more than a third of
patients have had this experience-but they are still in the minority.
A fundamental shift in attitude is required.

9 May 2013

Footnotes

190 This issue was recently discussed at an RNIB roundtable and key
issues are available for dissemination.
191 http://www.actionforme.org.uk
192 http://www.facebook.com/actionforme and www.twitter.com/actionforme
193 Aviva health of the nation index, 2013, p 22,
http://www.aviva.co.uk/library/pdfs/health/hotn-index-2013-gen4805.pdf