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>  
(...)  
  
Written evidence from Action for M.E. (LTC 40)  
----------------------------------------------  
  
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