

What is the MND Charter?

The motor neurone disease (MND) Charter is a statement of the respect, care and support that people living with MND and their carers deserve and should expect.

The five points of the Charter are:

- 1 The right to an early diagnosis and information**
- 2 The right to access quality care and treatments**
- 3 The right to be treated as individuals and with dignity and respect**
- 4 The right to maximise their quality of life**
- 5 Carers of people with MND have the right to be valued, respected, listened to and well-supported.**

The detail under the five points illustrates what good care looks like for people with MND and their carers. These details can be found in the full Charter document.

Why do we need a Charter?

People with MND and their carers commonly experience having to explain what MND is and what their needs are. This lack of knowledge and understanding, particularly among decision makers and health and social care professionals, can lead to people with MND experiencing problems accessing services that are responsive to their needs.

The Charter was created to help raise awareness and campaign to improve services for people with MND and their carers at a local level.

What is its aim?

To make sure everyone understands and respects the rights of people with MND and their carers so they are given the very best opportunity to access the care they need to live the highest quality of life possible, and achieve dignity in death.

Ultimately, it aims to support work towards achieving the vision of the right care, in the right place, at the right time for people with MND and their carers.

What has it achieved?

The Charter has helped raise awareness of MND and 33,630 individuals and organisations have signed up to the Charter.

It has led to work with health and social care professionals, national and local politicians and organisations, including councils, to improve services for people with MND and their carers.

See reverse for timeline

What now?

We want to build on the success of the MND Charter and continue to use it at a local level to raise awareness and create change for those living with MND.

We will do this through our campaign *Champion the Charter on your doorstep* urging councils across England, Wales and Northern Ireland to adopt the MND Charter.

Why councils?

Many decisions about services used by people with MND, such as social care, housing adaptations and support for carers, are made at the local level by councillors.

There are significant differences in the quality of services available to people with MND locally, depending on where they happen to live.

As such, it is important that councillors, and all those working for and with the council, understand the needs of people with MND and their carers.

What will it achieve?

By forming partnerships, we will help councils to raise awareness internally and, ultimately, achieve better outcomes for people living with the disease.

Our aim is that every time a councillor makes a decision, they think about the impact on people living with MND and their carers in the community.

As the focus of this campaign is local, the specific outcomes will depend on the area, and what change is needed.

We expect that the adoption of the Charter will be the first step in a lasting relationship with councils, where we work together to ensure people with MND get the right care, in the right place, at the right time.

How can my council adopt the MND Charter?

It's great that you want to get your council on board. We have prepared a pack with a step by step guide to help you do this.

You can download our guide from our website or request one to be sent to you in the post.

To find out more:

Visit: www.mndassociation.org/mndcharter

Email: campaigns@mndassociation.org

Phone: 0207 250 8447



**CHAMPION
THE CHARTER
ON YOUR
DOORSTEP**

The MND Charter
The journey so far...



PRESENT DAY

The Charter continues to be used in the local community to help raise awareness of the rights of people with MND and their carers



**CHAMPION
THE CHARTER
ON YOUR
DOORSTEP**

MARCH 2016

Launch of Champion the Charter



33,630 sign the Charter and it is presented to the Prime Minister at No. 10 Downing Street

JUNE 2015

MARCH 2015

Over **25,000** sign the Charter

MAY 2015

16 councils adopt the Charter



SEPTEMBER 2014

Launch of general election campaign urging parliamentary candidates to sign the Charter

OCTOBER 2014

700 Ice Bucket Challenge supporters also sign the Charter



20,000 sign the Charter

JUNE 2014



MAY 2014

Kent County Council becomes the first county council to adopt the Charter

JANUARY 2014

15,000 sign the Charter

MARCH 2014

Hundreds of councillors sign the Charter, and the Secretary of State for Communities and Local Government also signs!



JULY 2013

10,000 sign the Charter

SEPTEMBER 2013

Oxford City Council becomes the first council to adopt the Charter

Charter adopted in many countries around the world including, Turkey, Spain, Mexico, Italy, Australia, America, Colombia and Peru

JUNE 2013



MAY 2013

HRH The Princess Royal hosts MND Charter roundtable event

FEBRUARY 2013

Northern Ireland Health Minister Edwin Poots signs the MND Charter

JUNE 2013

British Dietetic Association sign the Charter

NOVEMBER 2012

Welsh Assembly members sign the Charter at a reception in the Senedd



5,000 sign up, including over 100 politicians, over 80 organisations and many VIPs including Prof. Stephen Hawking

OCTOBER 2012

NOVEMBER 2012

Royal College of Speech & Language Therapists and College of Occupational Therapists sign the Charter

AUGUST 2012

Royal College of GPs, Royal College of Nursing, Association of British Neurologists, Chartered Society of Physiotherapy sign the Charter

JUNE 2012

MND Charter launches



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