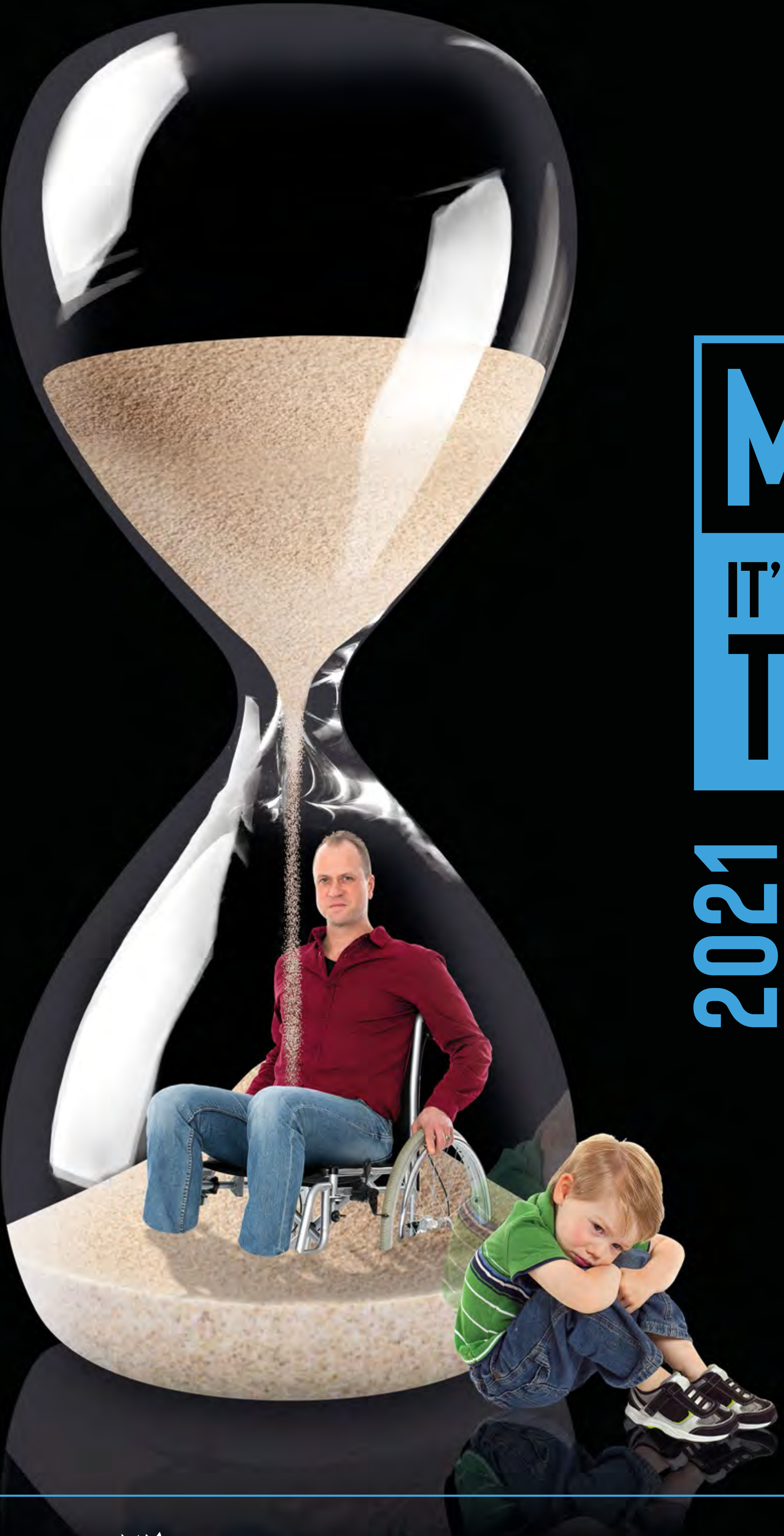


MND IT'S ABOUT TIME

2021 SCOTTISH PARLIAMENT ELECTIONS

MND Scotland

Manifesto

THE TIME TO ACT IS NOW

We don't have long...

Let's cut to the chase:

MND is brutally fast

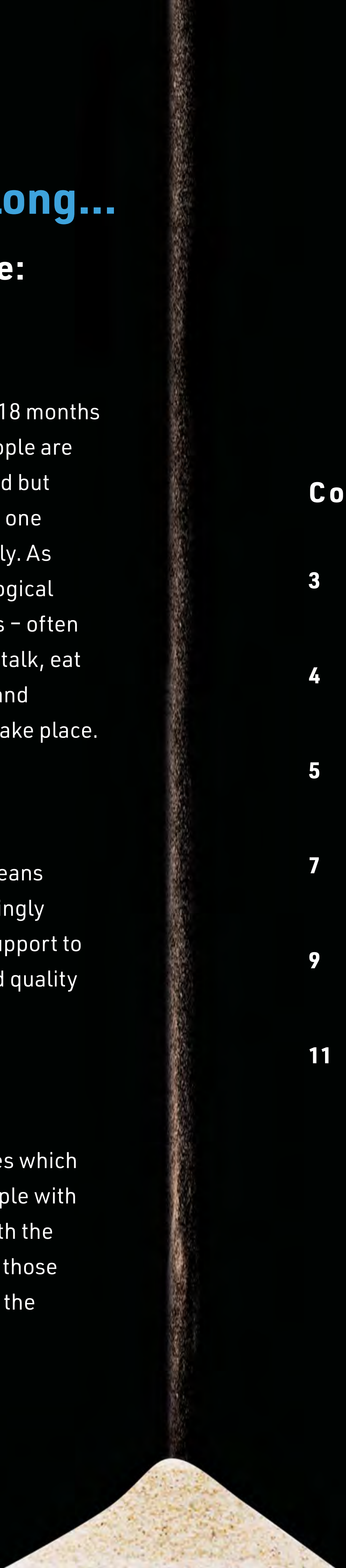
Average life expectancy is just 18 months from diagnosis. Almost 200 people are diagnosed each year in Scotland but only 400 have the illness at any one time because it moves so quickly. As MND progresses, rapid neurological degeneration leads to paralysis – often leaving people unable to walk, talk, eat or breathe unaided. Cognitive and behavioural changes can also take place.

We must act quickly

This merciless deterioration means people with MND need increasingly significant levels of care and support to enable them to maintain a good quality of life for as long as possible.

But we have a problem

Too often, the statutory services which should provide a lifeline to people with MND simply cannot keep up with the speed of deterioration, leaving those affected to struggle on without the help they urgently need.



Contents

The system can't Keep up

Statutory services cannot keep up with the speed of MND. MND Scotland's Advocacy service was set up to guide people through a labyrinth of confusing processes and be there when the system fails them.

The most common problems people affected by MND bring to us are accessing social care, home adaptations and accessible housing. People can wait months for these services – too many die still waiting.

This shouldn't be happening in 2021. People with MND should be able to spend the precious time they have left creating memories with loved ones.

Social Care

Home Adaptations

Accessible Housing

MND Scotland is calling for:

① *A National Care Service*

② *A National Accessible Housing Strategy*

Wide variations in practice across the country mean our Advocacy team is constantly fire fighting on a case-by-case basis.

People with MND need fast-tracked for these services equally and fairly across the country. To ensure this can happen, greater capacity is essential.

A national, strategic and human rights based approach is needed from the next Scottish Government.

The battle for
Social Care

At a time when people are coming to terms with a devastating terminal diagnosis, another battle often ensues as they seek to secure the care they need. Many find themselves waiting weeks for an initial care package to be put in place; even longer for it to be increased; and longer still (if at all) to secure overnight or 24 hour care, which can be essential when paralysis takes hold.

Unpaid carers plug the gaps, often looking after loved ones 24/7, while trying to hold down jobs, care for children, and look after their own health. Carer 'burnout' is a huge problem.

According to Carers Scotland, during the pandemic, carers saved the Scottish Government £43 million a day. Carers needs must be prioritised, especially those caring for someone with a terminal illness like MND.

MND Scotland is calling for:

A National Care Service for Scotland

Fast-tracking and planning

As a person with MND becomes increasingly disabled they will need increasing levels of care. Fast-tracking, anticipatory care plans and pathways are essential. Early planning for night time and 24 hour care must happen to ensure it can be put in place for those who need it as the disease progresses.

Choice and improved quality

‘Choice’ in care is a postcode lottery with rural areas particularly problematic. Some local authorities provide only in-house care while others outsource all care. SDS is not offered equally, or fully, to all. 15 minute care visits need replaced with an outcomes-based model of care and regular care workers are essential to ensure quality.

Prioritising carers

Prioritising carers and young carers of people who are terminally ill is critical. This should include improved identification and fast-tracked carers assessments. Implementation of timescales in the Carers Act to ensure quick access to support is needed. Person-centred, flexible respite for carers is essential.

Investing in a sustainable workforce

A sustainable care workforce is critical with a lack of staff being the reason given for delays. This has a devastating impact on families and can result in hospital bed blocking. Care work should be an aspirational career choice, with fair pay, Ts&Cs, training and progression. To become a reality, investment is essential.

Struggling without

Home Adaptations

While MND imprisons people inside their own body; the slow speed of the system often imprisons them inside their homes. Unable to move from room to room, wash, cook, or even get in and out of bed – accidents and isolation are an ever-present danger.

Homes must be adapted fast to accommodate needs: wetrooms installed, doors widened for wheelchairs, hoists and stair lifts fitted.

People affected by MND wait months for adaptations, with 28% of those who took part in our 2018 survey waiting more than 6 months for a wetroom. Others decide they don't have time to wait and pay thousands of pounds to get it done themselves. Yet getting adaptations put in place quickly can avoid lengthy stays in hospital and support carers and care workers to look after those with the illness safely.

MND Scotland is calling for:

A National Accessible Housing Strategy

Priority actions for ***Home Adaptations***

Fast-tracking people with MND

People with MND are frequently told they will wait a year or more for their adaptations. With little time on their side, many pay thousands of pounds to have them installed themselves. Adaptations make a huge difference to quality of life and systems to fast-track those with the illness must be put in place.

Simplified processes

There is a huge amount of red tape people with MND need to navigate. Some local authorities demand 3 quotes for a wetroom but people can find this difficult to obtain, causing lengthy delays. All local authorities should practically support people with this and processes need simplified, streamlined and standardised.

Anticipatory adaptations planning

In the knowledge that a person with MND will deteriorate quickly, anticipatory planning for adaptations, co-ordinated by a trained individual, could help reduce waiting times significantly and relieve the burden on families already struggling to cope with this devastating disease.

Investment in adaptations

As the population ages, demand will rise and delays will lengthen. This needs to be mitigated with investment, or people with MND will risk never getting the adaptations they need in time.

The long wait for

Accessible Housing

While home adaptations offer one avenue to maintain quality of life, for many they are not a viable option. For those who rent property, or live in inaccessible flats above ground level, a new accessible home is usually required.

Due to a lack of accessible housing, people with MND often need to apply for accessible social housing but there simply isn't enough to go round. People with MND can lose out to others with long-term conditions who have been on the waiting list longer. Rapidly progressing terminal illnesses like MND must be prioritised ahead of time on a waiting list. People with MND report pressure to move outside their local area, away from friends, family and care providers, or risk losing their place on the list.

MND Scotland is calling for:

A National Accessible Housing Strategy

Priority actions for ***Accessible Housing***

Fast-tracking people with MND

The systems used to match people to Scotland's accessible social housing are a postcode lottery and many, such as the 'bidding' choice based lettings, are completely unsuitable. Similarly, a waiting list is no use to someone with 18 months life expectancy. People with MND should be fast-tracked.

Cross-tenure standards and schemes

A space and quality standard for new homes would benefit people with MND, who rely on bulky equipment. Space, rather than number of rooms, should be prioritised. An identification and marketing scheme for accessible homes would establish if homes are truly accessible, speeding up processes and reducing pressure on social housing.

Empty homes made accessible

Empty homes, which could be made accessible, should be identified and adaptations made while general repairs are carried out. Relevant teams in local authorities must proactively work together to ensure this happens and that properties are directly matched to those who need them most, such as people with MND.

A national accessible housing target (10% minimum)

A lack of accessible housing across tenures, and across the country, leads to a squeeze on accessible social housing. However, demand cannot be met and people with MND don't have time to wait. A national target is needed, with accessible homes at the heart of future housing policy.

Pulling together

Leading politicians have already pledged to roll up their sleeves and pull together to help END MND (above).

We hope the next Scottish Government will see how essential these recommendations are to people affected by MND but also their wider value and benefit to many disabled people, older people and those who are terminally ill. We believe they can help pave the way for a more inclusive and equal Scotland.

Sincerely,

S Webster

Susan Webster

Craig W. Stockton

Craig Stockton

Susan Webster

Head of Policy & Campaigns

Craig Stockton

Chief Executive Officer

MND IT'S ABOUT TIME

2021 SCOTTISH PARLIAMENT ELECTIONS

Time is running out for people with MND

We're counting... on you

Who we are

MND Scotland is the leading charity in Scotland providing care and support to people affected by Motor Neurone Disease as well as funding vital research into finding a cure.

Scottish Charity No.

SC002662

Company limited by guarantee,
registered in Scotland no. SC217735

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Royal Patron

HRH The Princess Royal

Founder

John Macleod

MND Scotland

THE TIME TO ACT IS NOW