the british
psychological society
promoting excellence in psychology

# Psychological interventions for people with Huntington's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis

## Evidence-based guidance

January 2021

## AUTHORS

This guidance was facilitated by a grant from the Division of Clinical Psychology, part of the British Psychological Society and with the support of the BPS's Faculty for the Psychology of Older People (FPOP). The support and endorsement of the Division of Neuropsychology is also gratefully acknowledged.

**PROFESSOR JANE SIMPSON**

Lancaster University

**DR FIONA ECCLES**

Lancaster University

**DR NICOLÒ ZAROTTI**

Lancaster University

## ACKNOWLEDGEMENTS

The following (in alphabetical order) are gratefully acknowledged for their input in general or to the specific chapters

### GENERAL

**SARAH GUNN**

University of Leicester

**PROFESSOR NOELLE ROBERTSON**

University of Leicester

### HUNTINGTON'S DISEASE

**DR MARIA DALE**

Leicestershire Partnership NHS Trust

### MULTIPLE SCLEROSIS

**DR ANNABEL BROYD**

University College London
Hospitals NHS Trust

**DR CHRISTINE LONGINOTTI**

University College London
Hospitals NHS Trust

**DR AMANDA MOBLEY**

Worcestershire Health and Care NHS Trust

### PARKINSON'S DISEASE

**DR JENNIFER FOLEY**

University College London
Hospitals NHS Trust

**DR DOMINIC FFYTCHE**

King's College London

**PROFESSOR IRACEMA LEROI**

University of Dublin

**DR ANDREW PAGET**

University College London
Hospitals NHS Trust

### MOTOR NEURONE DISEASE

**DR EMILY MAYBERRY**

Sheffield Teaching Hospitals NHS
Foundation Trust

**DR NOORA OVASKA-STAFFORD**

University of Leicester

# Contents

CONTENTS

CHAPTER 1

# Introduction

# Introduction

## AIM

The aim of this guidance is to provide evidence-based recommendations for providing psychological support to individuals living with the following four motor neurodegenerative conditions: Huntington's disease, Parkinson's disease, motor neurone disease and multiple sclerosis. We have grouped these conditions together because they share some important similarities in terms of the psychological difficulties experienced by affected individuals, care pathways and the significant challenges encountered in providing psychological care and support for these populations (see also Chapter 6). However, as there are considerable differences between these four conditions in terms of, for example, age of onset, average length of time living with the condition, and symptom profile, the efficacy, approach, and adaptations to psychological interventions may also differ.

## FOCUS

This guidance focuses on psychological interventions for specific psychological outcomes in adults experiencing each of these four neurological conditions. We have excluded interventions developed solely for family members and carers as, though important, they are outside the scope of the current project. For Huntington's disease we have also included interventions for people who have received a positive genetic test result meaning they will go on to develop the disease, but have not yet developed symptoms, as individuals can still experience psychological difficulties in this period. However, we have excluded studies that focus on the test-taking period itself, including the decision whether to take the test, as this tends to be the remit of genetic counsellors in the UK and, again, is outside the scope of the current project.

## TARGET AUDIENCE

This guidance is for all psychologists, and other health professionals, who may work with individuals with these conditions and who wish to have easy access to up-to-date guidance and recommendations. For this reason, we have included a brief descriptive section on the conditions as we are aware that many professionals might be working with a person with such a condition for the first time. We have addressed the challenges around how to resource access to these effective ways of working in Chapter 6.

We focus here on the psychological approaches to address the identified psychological difficulties. We acknowledge that many difficulties will be addressed by multi-disciplinary teams and, as such, the approaches listed here may not be the sole therapeutic approach. We also acknowledge that psychological difficulties are linked to physical functioning and that improvements in physical functioning can improve psychological functioning. For some difficulties, for example pain or fatigue, other members of the team such as occupational therapists, physiotherapists and/or neurologists may take the lead. This guidance will be useful to inform such teams which psychological approaches may usefully contribute to multi-disciplinary care.

## THEORETICAL FRAMEWORK

We have adopted a psychological framework, and have not assumed that any difficulties are either just internally generated (i.e. via maladaptive cognitions) or the product of biochemical changes. We also acknowledge the influence of the social model of disability (see Simpson & Thomas, 2015), which shows the harmful psychological effects of living in a culture which views disability as an individual construct rather than as a result of an ill-equipped society which is sometimes poorly motivated to accommodate fully all those with physical impairments. Charities, such as the Scottish Huntington's Association's national care framework, are also using this approach.

## METHODS AND FORMAT

The format of this guidance is to provide evidence of effectiveness of psychological interventions for each neurodegenerative condition and, where studies allow, categorising this per psychological outcome and, again where studies allow, per type of psychological intervention. To achieve this, we carried out a systematic review of the current literature. The specific methods, the data extraction tables, and a more detailed report of the findings are also available online. Decisions regarding what to include as a target 'psychological' outcome were not always straight-forward, but we have erred on the side of inclusivity and so have included difficulties such as pain or fatigue, largely because these are often cause for referral to psychological services. We have also been inclusive regarding evidence design, largely because, for some conditions, no randomised controlled trials (RCTs – often seen as the 'gold standard' of outcome evaluation designs[1]) currently exist. This is particularly the case for Huntington's disease and to some extent motor neurone disease, where very little research has been conducted. Although our search was thorough and regularly reviewed, we acknowledge that some studies may have been missed, but we believe that any additions would not substantially change the conclusions of this guidance. Due to space limitations, the citations in the guidance are not comprehensive, but give examples of the relevant studies conducted. The full list is in the data extraction tables and more detailed report online.

## NOTES ON TERMINOLOGY

In this guidance we have been mindful of the BPS's position that we do not need to rely on diagnostic frameworks such as the *Diagnostic and Statistical Manual* (*DSM-5;* American Psychiatric Association, 2013). We have used the terms 'depression' and 'anxiety' as these tend to be used within the articles we have reviewed. However, we do not assume that such difficulties are always biologically mediated and have adopted a critical approach to studies that seem to overlook a multi-factorial causal perspective. While we do not rule out a biological contribution to psychological difficulties for some individuals, possibly via the same process that is responsible for the movement problems, we do not assume this. It is highly likely that in many cases (see also Garlovsky, Overton & Simpson, 2016; Mistry & Simpson, 2013; 2015) such difficulties have emerged from psychological precipitating factors. Such factors have been generally overlooked in searching for causal explanations

[1] While general details on research designs found by the literature review have not been included in this guidance, whenever the evidence discussed was from an RCT, this has been specified where appropriate within the text. For a more comprehensive discussion of all research designs please refer to the detailed report available online.

for psychological difficulties, although recent research has started to offer alternative, psychologically-derived explanations (Horne-Thompson & Bolger, 2010; Simpson et al., 2019a; Simpson, McMillan & Reeve, 2013). As a result of this conceptual position, we have not used terms such as neuropsychiatric or 'non-motor symptoms' to describe psychological difficulties.

We have tried to keep acronyms to a minimum but some were necessary for expediency and ease of reading. We have listed the acronyms at the end of the document along with a glossary explaining the different therapies referred to in the text.

## USE AND CITATION

This guidance is available to all interested in psychological approaches. We welcome your interest in its content, and if you have any comments or suggestions for further iterations, please contact us. For citation purposes, we ask that the following reference is used:

British Psychological Society (2021). *Psychological interventions for people with Huntington's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis: Evidence-based guidance.* Leicester: Author.

CHAPTER 2

# Huntington's disease

# Huntington's disease

Huntington's disease (HD) is a genetic neurodegenerative disease which affects around 12.3 persons per 100,000 in the UK (Evans et al., 2013) and around 2.71 per 100,000 worldwide (Pringsheim et al., 2012). It is caused by the mutation of a gene (HTT) located on the short arm of chromosome four which results in substantial damage to the basal ganglia, and in particular the corpus striatum. Typical motor symptoms include involuntary movements (chorea), difficulties with coordination, bradykinesia, dysarthria, and dysphagia, leading to complete loss of speech and ambulation (Roos, 2014; Roos, 2010; Walker, 2007). The typical age of onset is 35 to 45 years, but juvenile onset (before 20 and as early as 2) can also occur (Walker, 2007). Both men and women are affected by HD. No cure has been found so far and the mean life expectancy after the diagnosis is around 20 years (Folstein, 1989).

HD is hereditary and every affected individual has a 50 per cent probability of transmitting the expanded gene to their children. Anyone who inherits the expanded gene will, at some stage, develop the disease. Predictive genetic testing is available for individuals aged 18 and over with a family history, allowing them to know if they carry the gene expansion even decades before the onset of symptoms, but not when the onset will occur. The general uptake of predictive testing is very low, ranging between 15 per cent and 26 per cent in the UK (Quarrell & Rosser, 2014) and between 3 per cent and 24 per cent worldwide (Harper, Lim & Craufurd, 2000; Laccone et al., 1999). People with positive testing for HD without a formal diagnosis are usually referred to as 'gene carriers', 'presymptomatic' or 'premanifest' individuals (Dumas, van den Bogaard, Middelkoop & Roos, 2013)[1]. Those with family history of the disease who have not undergone genetic testing are usually defined as 'at-risk' (Chisholm, Flavin, Paulsen & Ready, 2013).

HD commonly causes a number of cognitive deficits, which ultimately lead to dementia. In people with manifest HD, impairments are often observed in memory, psychomotor speed, executive functioning, emotion recognition and regulation and, in later stages, language (Bates, Tabrizi & Jones, 2014; Dumas et al., 2013; Zarotti, Fletcher & Simpson, 2018). In premanifest individuals, executive processes and working memory tend to be mostly affected, although the current findings on long-term memory, emotion regulation and recognition, and language are less consistent (Labuschagne et al., 2013; You et al., 2014; Zarotti, Simpson, Fletcher, Squitieri & Migliore, 2018).

## PSYCHOLOGICAL DIFFICULTIES IN PWHD

Huntington's disease is associated with a number of psychological difficulties. Among the most frequent are depression, mood extremes, 'irritability' and aggressiveness (but see Simpson et al., 2019a), anxiety, agitation, compulsions and apathy (Dale & van Duijn, 2015; Roos, 2010; van Duijn et al., 2014). About 13 per cent of people may also show obsessive-compulsive behaviours (van Duijn et al., 2014). Delusions and hallucinations are usually rarer (Roos, 2010; Walker, 2007). An increased risk of suicide has often been observed in premanifest and manifest individuals (Hubers et al., 2012). Even more than the motor symptoms or pain (Ho & Hocaoglu, 2011; Underwood, Bonas & Dale, 2017), depression and cognitive impairments have been reported to be a highly significant determinant of quality of life in people with HD (pwHD) (Banaszkiewicz et al., 2012). In addition, a recent UK survey reported how the top care priority among pwHD and their families was to receive expert help for the mental health aspects of the condition (Smith et al., 2015).

Since the results of a predictive genetic test for HD can only confirm whether an individual

[1] For the purpose of this guidance, the terms 'premanifest' and 'manifest' will be used.

carries the expanded gene and will develop the disease, but not pinpoint when the onset will occur, a further psychologically challenging aspect of HD is the impact of predictive testing (Crozier, Robertson & Dale, 2014). As shown by the generally low uptake estimates, most at-risk individuals prefer to remain uncertain about their status and, when undertaken, the test usually coincides with important life choices, such as marriage or pregnancy. Research on those who get tested and receive a positive result have reported inconsistent findings. Some participants show normal levels of psychological distress but also increased appreciation for life and relationships after one year (Broadstock, Michie & Marteau, 2000; Duisterhof & Trijsburg, 2001), while others regret taking the test and develop a negative view of their future characterised by reduced engagement in education, jobs, family, or long term life plans in general (Hagberg, Bui & Winnberg, 2011). In some cases a positive test result has been associated with suicidal thoughts (Wahlin, 2007). From a systemic perspective, pwHD may also report genetic discrimination, i.e. being treated unfairly or differently by others due to genetic differences (Bombard et al., 2011; Williams & Erwin, 2010). Moreover, family issues, due to living with affected relatives and being part of the family narratives around the disease, especially when young children are involved, are often reported (Forrest Keenan et al., 2009; Zarotti, Simpson & Fletcher, 2019).

Given the widespread and multiple difficulties the disease causes, further exacerbated by the familial nature of HD, this condition can have a devastating effect across the lifespan of pwHD and family networks (e.g. see Sobel, 2005). For instance, it is known that attachment difficulties in children with parents with HD can affect their later mental health (van der Meer, van Duijn, Wolterbeek & Tibben, 2012), with childhood potentially affected by being parented by pwHD.

## PSYCHOLOGICAL INTERVENTIONS FOR PWHD

In spite of the wide range of psychological difficulties which can be experienced by pwHD (Dale & van Duijn, 2015; Simpson et al., 2019a; van Duijn et al., 2014), very little research has explored psychological interventions with this population. An education programme showed some benefits on several outcomes (A'Campo, Spliethoff-Kamminga & Roos, 2012), although generally more for manifest than pre-manifest individuals. No benefits have been shown from a pilot RCT adopting relaxation and sensory stimulation for those in a specialist residential unit for those with advanced HD (Leng et al., 2003). Hence, given the current severe paucity of research on psychological interventions for pwHD, no specific conclusions can be offered yet as to which psychological therapy may help this population. For a more in-depth review of the current literature, please see Zarotti, Dale, Eccles and Simpson (2020).

### RECOMMENDATIONS

Patient education programmes might help with general psychological functioning.

Given the lack of evidence on essentially all outcomes specifically for individuals with HD, practitioners are advised to refer to general guidance published by NICE for more common difficulties (e.g. depression in individuals with chronic conditions)

For the difficulties which are more HD-specific, e.g., irritability, given the lack of current evidence, we would suggest formulation-based approaches drawing on therapies generally recommended for anger – e.g., cognitive-behavioural (Lee & Digiuseppe, 2018) or possibly mindfulness-based approaches (Gillions, Cheang, & Duarte, 2019) – but incorporating acknowledgement of the powerful influence of uncertainty and lack of control on emotional responses.

Expert-based consensus clinical guidelines suggest non-pharmacological interventions (including psychological therapy) should be considered for psychological difficulties in pwHD before pharmacological ones (Anderson et al., 2018).

International guidelines for HD treatment (drawing on evidence for other neurodegenerative conditions) have suggested clinicians consider psychological approaches such as CBT as well as third wave cognitive therapies such as mindfulness and ACT for psychological difficulties (Bachoud-Lévi et al., 2019).

Given that many people with HD will live for a considerable time with both the knowledge that they have tested positive for the expanded gene and with the condition, resilience-based approaches might be helpful (e.g. Mindfulness-based cognitive therapy for life)

## SERVICE PROVISION FOR PWHD

The current access to psychological services for people with HD across the UK is patchy and unequal, with few psychologists with specific expertise in HD. People affected by HD are more likely to receive medication for for these difficulties and to be seen within a medical framework than a psychological one (Simpson et al., 2019a). Medical consultants often refer individuals to psychiatry rather than psychology, probably because of the lack of obvious care pathways. Where an individual's care lies with a neuropsychiatrist, then there is often a preference for this model to be used for all difficulties – psychological or motor. No survey of psychological provision currently exists for HD in the UK.

Few referrals are made to generic mental health services and, even when made, pwHD are often not accepted due to their complex multidisciplinary presentations. The Improving Access to Psychological Therapies (IAPT) programme in England has recently widened to address long-term conditions but this has not extended to neurological conditions, such as HD, and it is known that people with HD have trouble accessing generic psychological services or they can be unsuitable (The Neurological Alliance, 2017). This can lead to adverse consequences for pwHD who require specialist mental healthcare (The Neurological Alliance, 2017) and for physical, psychological, and social needs to be considered together (Scottish Huntington's Association, 2019a).

Recently, the National Care Framework for HD (Scottish Huntington's Association, 2019b), produced by the Scottish Huntington's Association in conjunction with a range of stakeholders including pwHD and their families, has highlighted clinical psychology/ neuropsychology to be among key services which should be provided for pwHD. Other studies involving HD families have identified the importance for clinicians to have experience and knowledge of HD (Dawson, Kristjanson, Toye & Flett, 2004). Such clinicians can work alongside the Huntington's Disease Association, Huntington's Disease Association Northern Ireland and Scottish Huntington's Association, who can provide help such as emotional support, family days, and education. Given the genetic nature of the condition, understanding the systemic factors at play is key (Maxted, Simpson & Weatherhead, 2014). Family therapy or other forms of systemic therapy are an important avenue to explore, but currently no research has been conducted in the post test period.

## ORGANISATIONS AND CHARITIES FOR HD

Third sector organisations which can provide information and support include: Huntington's Disease Association; Huntington's Disease Association Northern Ireland and Scottish Huntington's Association.

CHAPTER 3

# Parkinson's disease

# Parkinson's disease

Parkinson's disease (PD) is a chronic, progressive neurodegenerative condition caused in part by the death of dopaminergic neurons in the substantia nigra pars compacta. This results in dopamine deficiency within the basal ganglia, which leads to disorders of movement including bradykinesia (slowness of movement), muscular rigidity, rest tremor, and postural and gait impairment. These motor symptoms are heterogeneous in people with PD (pwPD), and clinical observations suggest two prominent subtypes: tremor dominant and non-tremor dominant (including akinetic rigid syndrome and postural instability gait disorder; Kalia & Lang, 2015). Other difficulties are also common and can include problems with cognition, affect, and sleep, as well as pain, gastrointestinal, and autonomic symptoms (Chaudhuri & Schapira, 2006; Weintraub & Burn, 2011).

Motor symptoms usually appear after the age of 50, although disease onset can be at a younger age, then known as young onset Parkinson' disease (Willis, Schootman, Kung & Racette, 2013). PD is the second most common neurodegenerative disease in older people (after Alzheimer's disease), affecting around one in 500 people in the UK (Mark, 2006). Worldwide prevalence estimates range from 1 to 418 per 100,000, and age specific prevalence increases until the ninth decade (Zhang & Roman, 1993). There is no definitive diagnostic test for PD, therefore the diagnosis is made clinically and is based on the presence of cardinal parkinsonian motor features, associated and exclusionary symptoms, and response to medication.

Currently no cure or disease modifying treatment is available for PD. Thus, a continuous reduction in physical functioning is inevitable as the disease progresses (Mark, 2006; Weintraub & Burn, 2011). The mainstay of treatment for PD has been the alleviation of motor symptoms through drug treatments that increase the concentration of dopamine or directly stimulate dopamine receptors in the brain. Initially, the symptoms of PD are typically well managed through medication, but, as the disease progresses, many complications begin to emerge, including those that are the result of long-term symptomatic treatment. These can include motor and non-motor fluctuations, dyskinesia, and psychosis. As more advanced stages are reached, the condition becomes less responsive to treatment and treatment resistant symptoms develop, such as freezing of gait, balance difficulties, falls, dysphagia, incontinence, and cognitive impairment. Considering that the life expectancy of pwPD is only slightly lower than that of the general population, this translates into many years of chronic illness and has a significant impact on pwPD and their families.

Cognitive deterioration in PD is common (Janvin, Aarsland, Larsen & Hugdahl, 2003), and tends to progress from mild deficits in selected domains of cognition, evolving to generalised mild cognitive impairment (PD-MCI; Litvan et al., 2012) through to dementia (PDD; Emre et al., 2007). Cognitive changes can be present at the earliest stages of the disease, with deficits in executive functioning most commonly observed (Foltynie, Brayne, Robbins & Barker, 2004), including alterations in working memory, cognitive flexibility, planning and attention, immediate memory, and processing speed (Foltynie et al., 2004; Muslimovic, Post, Speelman & Schmand, 2005).

## PSYCHOLOGICAL DIFFICULTIES IN PWPD

PD is most commonly recognised as a motor disorder and, as a result, psychological difficulties (and other problems outside the motor ones) are often under-recognised by healthcare professionals (Barbosa, 2013). Yet in addition to motor symptoms, pwPD are

often confronted by a range of psychological difficulties including depression, anxiety, cognitive impairment, apathy, impulse control behaviours, and other psychological problems, which may be treatment resistant. Indeed, psychological difficulties in PD are very common and can be as disabling as motor symptoms (Goldman & Holden, 2014; Truong, Bhidayasiri & Wolters, 2008), with their severity representing a key predictor of health-related quality of life (Leroi et al., 2011; Soh, Morris & McGinley, 2011).

Historically, our understanding of psychological difficulties in PD has been dominated by neurobiological conceptualisations (Brown & Jahanshahi, 1995). These assume that they occur as a result of pathological physiological processes, such as changes in dopaminergic systems (Chaudhuri & Schapira, 2009). More recently, however, it has been recognised that psychological difficulties in PD are likely caused by a combination of both neurobiological and psychological factors (Simpson, Lekwuwa & Crawford, 2013; Weintraub & Burn, 2011).

Psychological distress can occur at any time throughout the course of PD, either acutely, continuously, intermittently, or transiently. This may include mood disturbance prior to diagnosis; psychological reactions to the initial diagnosis, and changes experienced as the condition progresses; psychological disturbance caused by changes in neurotransmitter, inflammatory and neurotrophic factors; and the psychological side-effects of dopaminergic treatment (Even & Weintraub, 2012). In light of such complexity, multi-disciplinary team (MDT) approaches are advocated to provide specialist assessment and treatment. Given the multiple physical symptoms experienced by pwPD, it is likely that psychological interventions might also work best when physical symptoms are optimally controlled (although this is not to imply this relationship is one directional), hence the need for joined-up MDT involvement.

## PSYCHOLOGICAL INTERVENTIONS FOR PWPD

CBT has been found to have a positive effect on depression for pwPD – delivered in person individually (Dobkin et al., 2011), in a group (Troueng, Egan & Gasson, 2014), by telephone (Dobkin et al., 2020; Wuthrich and Rapee, 2019; Calleo et al., 2015) or the internet (Kraepelien et al., 2020) – with findings mainly from RCTs. Mindfulness-based interventions have also often reduced depression for pwPD at immediate follow up (Rodgers et al., 2019; RCT); Cash et al., 2015; Dissanayaka et al., 2016), although not universally (Pickut et al., 2015; RCT), as has a psychodrama intervention (Sproesser et al., 2010; RCT), but not psychoeducation interventions (Guo et al., 2009; RCT); Macht et al., 2007).

Interventions targeting anxiety with CBT (individually in person or by phone: Dobkin et al., 2020; Wuthrich & Rapee, 2019; RCT); Calleo et al., 2015; RCT) or in a group (Troueng, Egan & Gasson, 2014; RCT); Berardelli et al., 2018) have shown mixed outcomes, although many of these were characterised by small samples, However, some studies did report positive findings which were sustained up to six months (e.g. Dissanayaka et al., 2017; Troeung et al., 2015). Mindfulness-based interventions often (Dissanayaka et al., 2016; Kwok at al., 2019, RCT); Son & Choi, 2018; RCT) – (but not always (Rodgers et al., 2019; RCT) – improved anxiety, with effects lasting up to six months (Dissanayaka et al., 2016). A psychodrama intervention RCT also reduced anxiety (Sproesser et al., 2010).

Two studies adopting CBT (Hadinia et al., 2016; Troeung et al., 2014; both RCTs) and two using mindfulness (Birtwell et al., 2017; Dissanayaka et al., 2016) have reported a general reduction in stress in pwPD which has sometimes been sustained at longer term follow up.

Outcomes for both CBT RCTs (Hadania et al. 2016; Dobkin et al., 2020; Wuthrich & Rapee, 2019) and mindfulness RCTs (Son & Choi, 2018; Pickut et al., 2015; Advocat et al., 2016) for improving quality of life were mixed. In addition, RCTs adopting a group body awareness training based on ACT (Ghielen et al., 2017), a psychodrama intervention (Sproesser et al., 2010) and an education programme (Guo et al., 2009) improved quality of life, but another education programme studied in several countries (Macht et al., 2007) did not.

Considering psychosocial issues, a group psychoeducation programme was found to improve social adjustment at the two year follow up in an RCT comparing it to usual care for pwPD undergoing deep brain stimulation (Flores Alves Dos Santos et al., 2017; RCT). One CBT education programme found no change in psychosocial stress (Tiihonen, Lankinen & Viemerö, 2012), but another education programme led to improvements in psychosocial issues (Macht et al., 2007).

All the interventions which targeted sleep and incorporated CBT, including RCTs on a multicomponent sleep therapy (Leroi et al., 2010) and CBT for insomnia (CBTi) plus light therapy (Romenets et al., 2013), improved some aspects of sleep. Computerised CBTi improved sleep in another RCT for those who completed the intervention when compared to controls, but only 57 per cent completed it (Patel et al., 2017).

CBT or some of elements of CBT have also shown promise for helping with apathy (Berardelli et al., 2018; Butterfield et al., 2017) and impulse control difficulties (Jiménez-Murcia et al., 2012; Okai et al., 2013; RCT), although more research is needed here. No research was identified which targeted psychosis or more positive psychological constructs such as resilience, self-efficacy, and coping. For a more detailed review of the literature, please see Zarotti et al. (2020).

## RECOMMENDATIONS

CBT, delivered face to face, in groups, by telephone or online, has strong evidence for being effective for depression and, with less evidence, so do mindfulness and psychodrama.

CBT and mindfulness, and to a lesser extent psychodrama, can be helpful for anxiety.

CBT and mindfulness appear to be effective for stress.

CBT can be helpful for sleep-related difficulties.

For the more PD specific difficulties, CBT has had some success in reducing the impact of impulse control difficulties and apathy.

No psychological interventions have been assessed in relation to psychosis or specific psychotic phenomena (e.g. delusions or visual hallucinations), but there are general CBT-based approaches to these in the general population which could be adapted (see section on adaptations in Chapter 6 for further details).

Given that many people with PD will live for a considerable time with the condition, resilience-based approaches might be helpful (e.g. Mindfulness-based cognitive therapy for life).

## SERVICE PROVISION FOR PWPD

Due to the emphasis on the motor difficulties, pwPD are usually seen within specialist neurology or geriatric medicine settings and are under the care of a neurologist or geriatrician specialising in movement disorders. Yet, relatively few of these services have specialist psychological support available as part of the MDT, despite the high level of mental health problems among pwPD (Neurological Alliance, 2017). More generally, there remains a paucity of specialist mental health service provision for pwPD compared to other neurological conditions, and people can wait months or even years for support (All Party Parliamentary Group [APPG] for Parkinson's, 2018). NICE guidelines for Parkinson's disease (NICE, 2017) make no specific recommendations on how to support pwPD experiencing psychological difficulties, but refer to guidelines on depression in adults with a chronic physical health problem without recognition of common psychological difficulties in PD such as anxiety and apathy. SIGN guidelines only focus on diagnosis and medication (SIGN, 2010).

Previous position papers have stressed the need for specialist multidisciplinary PD clinics with input from mental health professionals integrated into the PD service, including those from neuropsychology, clinical psychology, and psychiatry (e.g. APPG for Parkinson's, 2018; BPS Professional Practice Board, 2009). Healthcare Improvement Scotland's Clinical Standards for Neurological Health Services (2019) and the Welsh Neurological Conditions Delivery Plan (2017) similarly emphasise the importance of integrated care for neurological conditions generally. These multidisciplinary services are best placed to understand the chronic and fluctuating nature of PD and the complex interactions between neurobiological and psychological factors. There should be an emphasis on early assessment allowing for effective management of psychological of difficulties (Shulman, Taback, Rabinstein & Weiner, 2002). Services also need to recognise that psychological difficulties change over the course of the progressive condition, trying to avoid a model of care where clients are assessed then discharged (Bender & Wainwright, 2005), but rather providing for psychological problems from the point of diagnosis through to palliative care. Special consideration should also be given to those with young onset PD, who constitute around 5–10 per cent of the PD population (Golbe, 1991). The needs of this subgroup differ in terms of occupational, financial, and familial responsibilities. They also differ in terms of the clinical manifestation and prevalence of psychological difficulties, with the younger onset population more likely to develop impulse control disorders (Ceravolo, Frosini, Rossi & Bonuccelli, 2010) and anxiety (Nègre-Pagès et al., 2010).

A few models of good practice already exist and were highlighted through the recent APPG on Mental Health in Parkinson's disease (Specialist Assessment and Rehabilitation Centre in Derby and Parkinson's Advanced Symptoms Unit in Teesside, UK) and through the Parkinson's UK Excellence Network for Mental Health (National Hospital for Neurology and Neurosurgery, London, UK). However, it is widely recognised that there are a number of constraints across the UK precluding optimal service provision, most notably in resources and shortages of key professionals. As such, most MDTs rely upon input from existing mental health services, typically commissioned separately, which can impede the ability to deliver integrated physical and mental health care (APPG for Parkinson's, 2018).

Where mental health support is not embedded within MDTs, provision of psychological therapies in England may be covered by Improving Access to Psychological Therapies Services (IAPT). NHS England's implementation of the five-year forward view for mental health recommends an expansion of IAPT services to provide support for people with long-term conditions. However, recent reviews suggest that IAPT at present may not be able to meet the needs of

pwPD (APPG on Parkinson's disease, 2018). Nonetheless, where therapies which can be provided through IAPT have been shown to be beneficial (e.g. CBT for depression) there is a strong argument for making these more available. This process could be part of a stepped care approach, with the option of access to more specialist clinical psychology support if needed. In Northern Ireland, mental health services are already not meeting their targets for waiting times and a shortage of specialist psychologists and neuropsychiatrists mean that, even if people manage to be seen, many will see mental health professionals with no knowledge of Parkinson's (APPG for Parkinson's, 2018; Northern Ireland Department of Health, 2019b). In Scotland, general access to mental health services can also be challenging and the needs of older people with mental health needs may not be identified, with a lack of appropriate training, skills, and multidisciplinary working (APPG for Parkinson's, 2018; Scottish Care, 2019). In Wales, the neurological conditions delivery plan (NHS Wales, 2017) acknowledges the shortage of psychology professionals, but there are no firm actions as to how this will be addressed (APPG for Parkinson's, 2018) and there is no specific Parkinson's pathway (APPG for Parkinson's, 2018). Thus, in all four nations services and professionals may lack the required knowledge and specialist supervision to adapt therapies taking into account the specific physical, cognitive, and psychological aspects related to the condition. Previous recommendations were that non-neuropsychologists could be utilised to deliver psychological therapies, but only under the supervision of clinical neuropsychologists or following additional specialist training (BPS Professional Practice Board, 2009). However, this is too restrictive and does not allow for the skills of other psychologists to offer input. Moreover, it is not feasible given the number of pwPD experiencing psychological difficulties and the corresponding number of psychologists available to offer support, or the more recent increase in the potential of digital health interventions. The recent APPG for Parkinson's disease (2018) made a number of specific recommendations for how services could be improved in this regard.

## ORGANISATIONS AND CHARITIES FOR PD

Third sector organisations which can provide information and support include: Parkinson's UK; Spotlight YOPD; Parkinson's Me.

CHAPTER 4

# Motor neurone disease

# Motor neurone disease

Motor neurone disease[1] (MND), also known as amyotrophic lateral sclerosis (ALS), is a neurodegenerative condition characterised by the progressive degeneration of upper and lower motor neurons (Hardiman et al., 2017). It leads to muscle weakness and wasting, loss of movement, speech and swallowing impairments, and reduced respiratory functioning. The average survival after the onset of symptoms ranges between three and five years, and no cure is currently available (Chiò et al., 2009; Worms, 2001). The worldwide incidence of MND is about 2 in 100,000 people (Logroscino et al., 2010; Marin et al., 2017), and up to 10 per cent of these are estimated to be due to a form of familial inheritance (Zarei et al., 2015).

The typical age of onset of sporadic MND ranges between 50 and 70, although it tends to occur earlier (40 to 50) in those with a hereditary variant (Andersen et al., 2012). The initial symptoms are usually subtle, and may include weakness in one of the limbs, difficulties with fine movements (e.g. buttoning up a shirt), foot drops while walking, wasting of the tongue, muscle twitches and cramps, and difficulties swallowing liquids (McDermott & Shaw, 2008). In the vast majority of cases, the onset of MND is characterised by weakness to one of the limbs, which then extends to the remaining ones, while other functions such as speech, swallowing, or breathing are usually affected at a later stage ('limb onset'; Chiò et al., 2009). However, around 30 per cent of pwMND experience another type of onset, which is characterised by early swallowing and speech difficulties due to involvement of the bulbar regions of the brain ('bulbar onset'; Hardiman et al., 2017). This represents an important distinction, since people diagnosed with bulbar MND generally have a poorer prognosis (Chiò et al., 2009), as well as higher levels of psychological distress (Goldstein, Atkins, Landau, Brown & Leigh, 2006; Hogg, Goldstein & Leigh, 1994). Swallowing difficulties along with breathing difficulties and possibly speech impairments have been associated with greater depression (Hillemacher et al., 2004).

The current clinical management of people with MND (pwMND) relies mainly on symptom management and palliative care, with the aim of improving or maintaining quality of life (Hobson & McDermott, 2016). With the progression of the disease, affected individuals can lose their ability to move, speak, and eat. In these cases, around the clock care becomes a necessity and measures such as non-invasive ventilation (NIV) and enteral feeding via a gastrostomy tube may be adopted to prolong survival (Andersen et al., 2012; Hardiman et al., 2017; Martin et al., 2016).

While MND was traditionally thought to affect only motor neurons without altering cognitive skills (Phukan, Pender & Hardiman, 2007), more recent evidence has triggered renewed awareness on the neuropsychological impact of the disease. This has shown that between 40 and 50 per cent of pwMND experience forms of cognitive impairment, in particular in the areas of executive functioning, language, and verbal fluency (Abrahams, 2013; Niven et al., 2015). Moreover, about 10–15 per cent of pwMND meet the full criteria for a diagnosis of frontotemporal dementia (Phukan et al., 2012; Ringholz et al., 2005), and some authors have proposed that there might be a cognitive and behavioural continuum between the two conditions (Lillo, Savage, Mioshi, Kiernan & Hodges, 2012; Murphy et al., 2007).

## PSYCHOLOGICAL DIFFICULTIES IN PWMND

Since no specific test for MND is currently available, the diagnosis typically consists of multiple medical examinations aimed at excluding any conditions with similar symptoms. This frequently translates into a long and uncertain path to diagnosis, lasting on average 10 to 18 months (Andersen et al., 2012). This may, in turn, lead affected individuals to experience

[1] While we are aware of the different spellings for neurone/neuron, we have chosen 'neurone' as this is used by the Motor Neurone Disease Association

high levels of anxiety and depression (Mistry & Simpson, 2013; Oliver, Borasio & Walsh, 2011), and to develop coping strategies based on denial and avoidance (Maes, Leventhal & de Ridder, 1996; Stanton & Revenson, 2012; Zarotti et al., 2019), which can lead to poorer quality of life (Hogg et al., 1994; Lee et al., 2001).

Even before a diagnosis is made, the physical symptoms of MND can affect a person's independence, social roles, identity, confidence, and self-esteem. People with bulbar onset MND generally show higher levels of psychological distress (Goldstein et al., 2006; Hogg et al., 1994), and research indicates that breathing, swallowing, and speech difficulties are associated with this distress (Hillemacher et al., 2004). For example, dysarthria can impact psychosocial factors (Hecht et al., 2002; Walshe, Peach & Miller, 2009), leading to changes to perceived identity, feelings of self-consciousness, and negative emotions (Dickson, Barbour, Brady, Clark & Paton, 2008; Walshe & Miller, 2011). Dysphagia has been linked to fear of choking (Greenwood, 2013; Muscaritoli et al., 2012), loss of pleasure deriving from eating (Johnson et al., 2012; Stavroulakis et al., 2014, 2016), and loss of control (Foley, Timonen & Hardiman, 2014; Zarotti et al., 2019). However, with the exception of fear of choking, many of these psychosocial and emotional consequences of physical MND symptoms would also apply to people with limb onset MND. In addition, regardless of the site of onset, the condition is progressive, and many people eventually develop a combination of limb and bulbar symptoms (Hardiman et al., 2017). Therefore, the losses are cumulative and significant adjustment must continue throughout the course of the disease (Hobson & McDermott, 2016).

As noted above, some degree of cognitive impairment is relatively common. As cognitive flexibility and flexible affective processing both represent predictors of trait resilience (Genet & Siemer, 2011), cognitive impairments are likely to affect the emotional coping abilities of pwMND, as well as their response to psychological treatment (Zarotti, Mayberry, Ovaska-Stafford, Eccles & Simpson, 2020).

## PSYCHOLOGICAL INTERVENTIONS FOR PWMND

Similarly to HD, research on psychological interventions involving pwMND is still very limited. Based on the evidence currently available, levels of anxiety and depression may be reduced and quality of life may be improved by specially adapted versions of mindfulness (Pagnini et al., 2017), individual CBT (Díaz et al., 2016; Van Groenestijn et al.,2015), and an individual psychodynamic approach with hypnosis (Palmieri et al., 2012; Kleinbub et al., 2015). Most interventions also involved carers/family members.

One additional study looked at dignity therapy with pwMND and their carers, including those who used augmentative and alternative communication tools (Aoun, Chochinov & Kristjanson, 2015). Although changes in quality of life were not significant, the therapy was well-received and this study is notable for enabling those with reduced communication abilities to access therapy.

As a previous systematic review also concluded (Gould et al., 2015), currently it would be premature to suggest more conclusively which psychological interventions may help pwMND. Nonetheless, the initial indications are that psychological interventions are unlikely to be harmful and have the potential to be helpful. However, only the results from Pagnini et al. (2017) and Van Groenestijn et al. (2015) were based on RCTs, and the very limited number of studies means that we are still lacking enough evidence to make evidence-based recommendations about the efficacy of psychological interventions, or to comment on which specific therapy models are most effective. For more details on the current literature, please see Zarotti, Mayberry, Ovaska-Stafford, Eccles, and Simpson (2020).

### RECOMMENDATIONS

Mindfulness and individual CBT might be effective for anxiety and depression in pwMND, with more limited evidence for individual psychodynamic approaches along with hypnosis.

Given that many people with MND will only live for a relatively short time with the condition, resilience-based approaches might be helpful (e.g. Mindfulness-based cognitive therapy for life) although these might have to be adapted away from the group format to ensure a more timely delivery and taking into account individual needs (see section on adaptations in Chapter 6 for further details).

Multi-disciplinary approaches to prolonging quality of life are likely to be well-received given the often rapid onset of motor problems and the imperative to respond quickly to changing health-related quality of life needs.

## SERVICE PROVISION FOR PWMND

NICE guidelines (2016) suggest that the psychological and emotional impact of MND and the psychological needs of pwMND should be discussed at MDT assessments and other appointments and that the person should be referred to counselling or psychological services if specific support is needed. However, access to dedicated psychological support is patchy across the UK, with some specialist hospital services (including MND care centres) having access to psychology, but only a few having psychology or neuropsychology integrated within the team. The same is true for community neurological rehabilitation teams. Some community services have access to psychology, but this is not consistent across geographical regions. Specialist nurses and other members of the care team inevitably (and appropriately) provide some psychological support. However, their roles tend to be more focused on physical care needs, and they often do not have the time or the training to do more in-depth psychological work.

In some areas, hospices offer counselling support to pwMND, and sometimes also to their family members. However, this depends on the set-up of the hospice and is not available everywhere. In addition, some counsellors might not have appropriate training or experience to address specific requirements when pwMND present with significant cognitive or communication difficulties.

PwMND could potentially access generic mental health services (e.g., improving access to psychological therapies [IAPT] in England), but such services tend to treat specific mental health problems. Moreover, practitioners would not always have experience working with people who have a physical health problems, let alone one that is life-limiting and rapidly progressive, where quick access to services is therefore needed. For pwMND experiencing depression, NICE guidelines for MND (NICE, 2016) refer to the NICE guidelines for treatment of adults with depression and a chronic health problem (NICE, 2009). However, difficulties in accessing mental health services and receiving appropriate care have been generally recognised for people with neurological conditions (Neurological Alliance, 2017), and pwMND have commented that healthcare providers usually seem to lack knowledge of MND (NICE, 2016). Therefore, there is a risk that such appointments could pathologise normal shock and grief responses to this disease and either be ineffective or actively unhelpful. In addition, due to the nature of the work and the short appointments, accessing support through mental health services would only be feasible for individuals who are in the early stages of the disease or who do not have significant cognitive or communication difficulties, as both these and psychological needs can change rapidly through the disease course (NICE, 2016).

The motor neurone disease third sector organisations, such as the MND Association and MND Scotland, are valuable resources, with volunteers, information leaflets, and members of staff who can provide some support and help signpost pwMND to local services. In addition, MND Scotland has a counselling service. However, these organisations do not provide more in-depth psychological support, and instead rely on adequate local services being in place. Where support is not available through the NHS or other public sector or charitable organisations, the only other option would be for people to access private therapy. Obviously, this has cost implications and would exclude some people from accessing the help they need.

## ORGANISATIONS AND CHARITIES FOR MND

Third sector organisations which can provide information and support include: MND Association and MND Scotland.

CHAPTER 5

# Multiple sclerosis

# Multiple sclerosis

Multiple sclerosis (MS) is a chronic inflammatory autoimmune neurological[1] condition that affects the central nervous system (CNS) and causes damage to myelinated axons. The course of MS is unpredictable, a function of both the location of lesions and auto-inflammatory processes (Goldenberg, 2012). At present, MS is treatable but not curable, and continues to represent one of the most common causes of physical disability in young adults (Brownlee, Hardy, Fazekas & Miller, 2017). Prevalence estimates vary within the UK and the channel islands and range from 96 per 100,000 in Guernsey to more than 200 per 100,000 in Scotland and Northern Ireland, and both prevalence and incidence appear to be increasing (Kingwell et al., 2013).

Diagnosing MS can be challenging due to the varied locations of lesions in the CNS, which can be associated with a wide range of symptoms and presentations (Brownlee et al., 2017). This can sometimes lead to a delay in diagnosis, or even misdiagnosis (Edwards, Barlow & Turner, 2008). Moreover, MS may present in different phenotypes that vary in clinical course (Lublin, 2014). Relapsing-remitting MS (RRMS) is the most common presentation, affecting up to 85–90 per cent of people diagnosed with MS (Polman et al., 2011), and is characterised by periods of remission alternated with unpredictable relapses, which cause the onset of acute symptoms (Loma & Heyman, 2011; Siddiqui et al., 2018; Weiner, 2008). Primary progressive MS (PPMS) is a less common variant which follows a progressive course from the time of diagnosis, while secondary progressive multiple sclerosis (SPMS) is characterised by the evolution towards a progressive trajectory following a relapsing-remitting onset (Lublin, 2014). Finally, prior to receiving a formal diagnosis, a person may be diagnosed with Clinically Isolated Syndrome (CIS) or Radiologically Isolated Syndrome (RIS). In these a person may show symptoms or radiological signs indicative of demyelination, but there is insufficient evidence to diagnose MS formally (Lublin et al., 2014).

## PSYCHOLOGICAL DIFFICULTIES IN PWMS

MS is linked with a wide range of psychological difficulties, and people with MS (pwMS) often report lower quality of life (McCabe & McKern, 2002) and increased psychological distress, even when compared to other neurological conditions (Brands, Bol, Stapert, Köhler & van Heugten, 2018; Ryan et al., 2007). In addition, it has long been hypothesised that psychological factors may also impact physical health for pwMS. MS was first diagnosed by Jean-Martin Charcot in 1868, who later suggested that psychosocial stressors such as changes in social circumstances may trigger or exacerbate MS symptoms (Charcot, 1877). Indeed, in recent times psychological stress has been found to be associated with exacerbation of MS symptoms (Mohr et al., 2004), and interpersonal stress has been positively associated with brain lesions on magnetic resonance imaging (Mohr et al., 2000; Mohr et al., 2012). This suggests a complex interplay between psychological factors and physiological factors for pwMS.

Since the 1940s, depression has been widely studied in pwMS (Canter, 1951; Philippopoulos, Wittkower & Cousineau, 1958; Siegert & Abernethy, 2005), whereas anxiety has comparatively been less well researched (Marrie et al., 2015). However, depression and anxiety are known to be more common difficulties for affected individuals compared to the general population (Feinstein, Magalhaes,

[1] Whether MS should be classified as an immune or neurodegenerative disease is a matter of debate, although it has been argued that the primary cause of neurological impairment is neurodegeneration (Trapp & Nave, 2008).

Richard, Audet & Moore, 2014; Hoang, Laursen, Stenager & Stenager, 2016; Janssens et al., 2003), and they appear frequently together in the condition (Marrie et al., 2013; Marrie, Reingold, et al., 2015; Wood et al., 2013).

In addition, as MS follows a variable course due to the position of lesions in the CNS (Brownlee et al., 2017), it can be difficult to predict the clinical course and impact of symptoms (Langgartner, Langgartner & Drlicek, 2005). This unpredictability, as well as the uncertainty around future functional levels, may contribute to the high co-occurrence between anxiety and depression. As MS progresses, new symptoms can emerge that may have a significant impact on daily life and cause psychological distress (Irvine, Davidson, Hoy & Lowe-Strong, 2009). People who are more physically affected by MS report higher rates of depression compared to those with fewer physical symptoms (Chwastiak et al., 2002). However, psychological adjustment can vary over the course of the illness and in one study, people who had a shorter duration of MS were more likely to experience significant depressive symptoms than those with longer duration (Chwastiak et al., 2002). The unique and wide-ranging uncertainties associated with MS (Barker-Collo, Cartwright & Read, 2006) can impact on how well a person adjusts to their diagnosis (Dennison, Moss-Morris & Chalder, 2009; Irvine et al., 2009), with people who perceive greater uncertainty showing poorer adjustment to their illness (Sullivan, Wilken & Rabin, 2004).

## PSYCHOLOGICAL INTERVENTIONS FOR PWMS

Among the conditions covered by the present guidance, MS was by far the most researched in terms of psychological interventions, with depression and low mood being the most frequently targeted difficulties. Individual CBT was effective at reducing depression (Mohr et al., 2001; Kirolpoulos et al, 2017), as were telephone (Ehde et al 2015; Mohr et al., 2005 Mohr et al., 2000a), computerised (Fischer et al 2015), and group CBT (Graziano et al., 2015; Larcombeand et al., 1984; Lincoln et al., 2011); findings largely from RCTs. For some studies the effect was maintained at six months and beyond, including three RCTs (e.g. Ehde et al., 2015; Mohr et al., 2001; Mohr et al., 2005). RCTs using mindfulness-based approaches, whether delivered in person (Carletto et al., 2017; Grossman et al., 2010; Simpson et al., 2017) or via video calls (Cavalera et al., 2018), also reduced depression levels, although often the effects decreased more long-term. Outcomes were mixed for ACT, but it has been little studied (Masjedi-Araani et al., 2018; Nordin & Rorsman, 2012) , with only one RCT (Nordin & Rorsman, 2012). Approaches which reduced depression in a single RCT included supportive-expression therapy (Mohr et al., 2001) and insight-oriented therapy (Crawford & McIvor, 1985), although the former less so than individual CBT. A self-management intervention showed a trend towards reducing depression (Barlow et al., 2009). Other studies also looked at positive psychology (Leclaire et al., 2018), a wellness programme (McGuire et al., 2015), a social cognitive treatment (Jongen et al., 2016), DBT (Blair et al., 2007), and various integrative treatments, showing either significant decreases in depression or decreases at a trend level.

Higher quality anxiety intervention studies (i.e. RCTs) have been mainly group-based. Group CBT was effective both for anxiety generally (Pahlavanzadeh et al., 2017; Robati & Shareh, 2018) and OCD (Sayyah et al., 2016). Mindfulness-based groups (Cavalera et al., 2018; Kolahkaj & Zargar, 2015; Simpson et al., 2017) were also effective for anxiety, although it is unknown whether effects were maintained for more than six months. One individual RCT CBT study also showed some improvement in anxiety (Lincoln et al. 2011). ACT was less well studied with only two RCTs; a bibliotherapy self-help intervention found improvements (Proctor et al., 2018), and

a short group ACT intervention had outcomes no different from relaxation (Nordin & Rorsman, 2012). An RCT studying EMDR and relaxation for PTSD in pwMS found both had positive effects, but EMDR was more effective and the effects were maintained at six months (Carletto et al., 2016). A psychoeducational MS wellness programme (McGuire et al., 2015) and a self-efficacy programme (Jongen et al., 2016) also reported positive findings, althought the latter was effective for RRMS, but not PPMS. No changes in anxiety were found for an integrative approach including perceptions of body image (Tesar et al., 2003), insight-oriented psychotherapy (Crawford and McIvor, 1985), positive psychotherapy (Leclaire et al., 2018) as well as positive psychotherapy combined with CBT (Anderson et al., 2017). However, with only one or two studies focusing on each and long-term follow ups generally lacking, it is harder to draw conclusions for these.

One RCT (Pahlavanzadeh et al., 2017) suggested stress was improved by group CBT interventions. RCTs using mindfulness-based interventions were also largely (Kolahkaj & Zargar, 2015; Senders et al., 2018; Simpson et al 2017) – but not universally (Agland et al., 2018) – effective in reducing stress at immediate follow up. A psychoeducational MS wellness programme (McGuire et al., 2015) also reduced stress in one study. However, the long-term effects are unclear for all these approaches.

Fatigue has also been well studied. Individual CBT, delivered in person (van Kessel et al., 2018 van den Akker et al., 2017), by telephone (Ehde et al., 2015), and online (Moss-Morris et al., 2012; Pottgen et al 2018; Van Kessel et al. 2016) has been found to be effective at reducing fatigue, including up to six months or more (e.g. Ehde et al., 2018; van Kessel et al., 2008) in RCTs. However, long term follow up data were not collected for the online programmes and one study had a low completion rate, without additional support (van Kessel et al., 2016). Outcomes from group programmes with CBT elements were mixed (Thomas et al., 2013 (RCT); Wendebourg et al., 2016), but the groups were quite different in design and one programme studied in an RCT had positive effects up to a year (Thomas et al., 2014). Outcomes from mindfulness-based interventions were largely (but not always) positive (e.g., Grossman et al., 2010; RCT); Cavalera et al., 2018; RCT); Hoogerwerf et al., 2017). However, it is unclear how important specific elements of mindfulness-based interventions are for reducing fatigue (Bogosian et al., 2015; RCT); Spitzer & Pakenham, 2018). RCT findings suggest relaxation may also improve fatigue (Sgoifo et al. 2017; Carletto et al., 2016), but the long-term effects are not clear and one RCT suggested CBT may be more effective than relaxation (van Kessel et al., 2008). Finally, a social-cognitive wellness programme (Jongen et al., 2016) failed to reduce fatigue, while a self-management programme involving CBT and positive psychology reported positive results (Anderson et al., 2017).

Regarding sleep, CBT, particularly with sleep specific components, appeared to be a promising intervention for pwMS (Abbasi et al., 2016; RCT). Mindfulness delivered via video call (Cavalera et al., 2018; RCT) may be helpful, but benefits were not retained after six months. Relaxation also appeared to offer benefits from the one study (Dayaploglu & Tan, 2012), but further research is needed to see whether the benefits can be maintained long-term.

A number of investigations used more global assessments of adjustment, although this term was not used consistently by all. CBT RCTs showed some evidence of improved adjustment, but not universally at one year follow up (Mohr et al., 2007; Moss-Morris et al., 2013; Forman & Lincoln 2010). One feasibility RCT compared individual and group CBT and found similar results, although the individual sessions were better attended, with a trend towards better outcomes (Das Nair et al., 2016). One study looked specifically at sexual adjustment using a 'mindfulness psychoeducational' programme

with non-significant main outcome (Hocaloski et al., 2016).

A half day ACT workshop, (Sheppard et al., 2013) and a relationship enhancement programme (Tompkins et al., 2013) both found positive effects on psychosocial wellbeing at short-term follow up. When considering quality of life and wellbeing, group CBT findings were also largely positive for improving at least some aspects of quality of life and/or wellbeing at immediate follow up (Graziano et al., 2014; RCT); Calandri et al., 2017; Mohr et al., 2005). Mindfulness-based RCTs also had largely positive findings at immediate follow up, but more mixed longer-term outcomes (Cavalera et al., 2018; Grossman et al., 2010; Agland et al, 2018). Supportive-expressive therapy, illness education, a social-cognitive wellness programme, and positive psychology all had one study showing largely positive effects on quality of life (Abolghasemi et al., 2016; Jongen et al., 2016; Leclaire et al., 2018). However, only the evidence for supportive-expressive therapy was based on an RCT (Abolghasemi et al., 2016).

Studies looking at coping (e.g., Foley et al., 1987; Feicke et al., 2014; Tesar et al., 2003) and resilience (Rigby et al., 2008; Pakenham et al., 2018) generally found positive effects. However the approaches were generally quite different, involving aspects of CBT, relaxation, ACT, education about MS, and social discussions. Moreover, only two studies (Foley et al., 1987; Rigby et al., 2008) were RCTs, so it is hard to be conclusive about specific interventions. Similarly, there were some promising findings from studies looking at hope (Abolghasemi et al., 2016; Feicke et al., 2014; Anderson et al., 2017), but mixed findings from studies looking at optimism (Leclaire et al., 2018; Caladri et al., 2017) with a variety of approaches utilised, including supportive expressive therapy, self-management, CBT, and positive psychology. However, high quality RCTs for these outcomes were lacking.

Self-efficacy improved in two RCTs adopting group CBT (Graziano et al., 2014, Rigby et al., 2008). Outcomes from self-management programmes (Barlow et al., 2009; RCT); Hemmati Maslakpak & Raiesi, 2014; RCT); Feicke et al., 2014) and a social cognitive wellness programme were also largely positive, although the latter was for people with RRMS and not PPMS (Jongen et al., 2016).

Both CBT and psychoeducation were shown to be effective at reducing pain in pwMS in an RCT (Ehde et al., 2015), with the effects being sustained up to 12 months. The approaches investigated by the other studies involving elements of CBT and ACT (Harrison et al., 2015) or hypnosis (Jensen et al., 2011) also suggest this is an area for further exploration.

One RCT (Mohr et al., 2005) comparing telephone CBT against supportive emotion-focused therapy found greater improvements in positive affect for CBT post-intervention, with benefits retained at one year (though group differences disappeared). Other studies on positive and negative affect including CBT (Sinclair & Scroggie, 2005; Calandri et al., 2017), mindfulness (Gilbertson & Klatt, 2017), and positive psychology (Anderson et al., 2017; Leclaire et al., 2018) reported mixed findings. This was also the case for two studies on group CBT (Robati & Shareh, 2018) and insight-oriented therapy (Crawford & McIvor, 1985) for self-esteem.

A study adopting group CBT for body image (Tesar et al., 2003) showed inconclusive findings Similar results were also reported by an RCT utilising group CBT for identity and sense of coherence (Graziano et al., 2014). On the other hand, a study focusing on personality and temperament (Crescentini et al., 2018) found that MBSR may lead to some positive changes in pwMS. No investigations have been carried out to address apathy specifically, but other studies gave an indication that related constructs of activation and initiation can change as a result of self-management (Ehde et al., 2018; RCT) or psychodrama (Langenmayr & Schottes, 2000). Considering the impact of apathy on pwMS, this area is also worth further study.

## RECOMMENDATIONS

Most variants of CBT, including telephone- and computer-administered (though see caveats in Chapter 6) as well as individual and group-based, are recommended for low mood and depression in pwMS.

Mindfulness, delivered in groups either in person or via videocall, is also recommended for low mood/depression.

Group-based interventions using either CBT or mindfulness are recommended for anxiety.

Group CBT and mindfulness interventions are recommended for stress.

Many variants of CBT – online (see caveats in Chapter 6), in person, and by telephone – are recommended for fatigue. Mindfulness approaches might also be effective.

Specially adapted CBT – and, to some extent, mindfulness approaches – is recommended for sleep problems.

A number of approaches could be recommended for improving psychosocial well-being and quality of life, including group CBT and mindfulness.

For positive growth, coping, self-efficacy, and resilience approaches drawing on CBT, positive psychology, supportive expressive therapy, ACT and/or self-management may be useful, although more rigorous research is needed in these areas.

No MS specific approach has been assessed for apathy, but general psychological and activity-based approaches might be useful.

## SERVICE PROVISION FOR PWMS

Health Improvement Scotland (2019) recommends people with neurological conditions should receive coordinated person-centre care involving a holistic assessment of a person's needs, including psychological and emotional needs. Similarly, NHS Wales Neurological Conditions Delivery Plan (2017) highlights the need for holistic approaches including psychological and emotional wellbeing and the need for integrated and coordinated care. More specifically, NICE guidelines for MS (NICE, 2014) recommend that care for affected individuals should be via a multidisciplinary approach with one person coordinating the care. NICE guidelines recommend that pwMS have a comprehensive review at least once a year of all symptoms and difficulties, and that this should include a review of issues with anxiety, depression, sleep, fatigue and pain, with the aim to refer the pwMS to an appropriate professional. The guidelines do not specifically mention psychological approaches for depression or anxiety, but refer to the general guidelines for managing depression in people with long-term health conditions (NICE, 2009) and general guidelines for managing anxiety in the general population (NICE, 2011). However, as they do note that pwMS with fatigue should be assessed and given access to psychological support for anxiety, depression, and sleep difficulties (which may be impacting on fatigue), they also mention mindfulness-based therapies, CBT, and fatigue management as possible approaches to alleviate fatigue.

NICE guidelines for the general population with chronic health conditions (NICE, 2009) state that treatment for depression should follow a stepped care model. Thus, depression will usually be highlighted in primary care

services as a first step, where the pwMS can be initially assessed and monitored, and referred onto an appropriate service for further assessment and intervention. Low-intensity psychological interventions (computerised CBT, group-based peer support, or self-help based on CBT principles) are recommended for mild to moderate depression, alongside physical activity programmes and psychoeducation. High-intensity interventions (group or individual CBT, or behavioural couple therapy) are advised for severe or complex depression, or mild to moderate depression that has not responded to low-intensity interventions. Antidepressant medications – generally selective serotonin reuptake inhibitors (SSRIs) – may be offered in conjunction with psychological interventions for more refractory or severe presentations of depression.

While there are no guidelines specific to anxiety and MS or long-term conditions, guidance for the general population highlight a similar stepped care model for treatment of generalised anxiety disorder (NICE, 2011). This also suggests initial identification and assessment as a first step, followed by low-intensity treatment for mild to moderate anxiety, and high intensity treatment for people who do not respond to low-intensity interventions, or are characterised by complex presentations, high levels of risk, or very marked functioning impairment. Again, low-intensity treatments will comprise individual self-help, guided self-help, or psychoeducational groups – all based on CBT principles. High intensity input involves the patient choosing between CBT or applied relaxation, lasting 12 to 15 weeks, alongside potential pharmacological treatments (usually SSRIs).

In terms of accessing help for psychological difficulties for a person living with MS, their clinical nurse specialist or GP will be the first point of contact for any concerns. Access to either a neuropsychologist or psychologist via a local neurological service is very variable across the UK. A referral to a mental health service such as Improving Access to Psychological Therapies (IAPT) in England will often be suggested to help with feelings of depression and anxiety in the first instance (Methley, Campbell, Cheraghi-Sohi & Chew-Graham, 2017). IAPT services provide short-term CBT and usually accept self-referrals, meaning a person can make the referral themselves and they do not need to go through a GP or health professional. However, surveys by the Neurological Alliance of people with neurological conditions in England (2019) suggested that accessing such services could be difficult or that healthcare professionals may not have the relevant expertise to help. While it is unclear to what extent this applies specifically to pwMS, one small study of pwMS, GPs, practice nurses and specialist nurses in the North West of England (Methley et al., 2017) suggested that accessing appropriate mental health support could be problematic. The nurses did not feel confident dealing with mental health needs and could feel stuck as there was no specialist mental service to which pwMS could be referred and eligibility for generic mental health services was variable. While a few GPs and specialist nurses suggested that services were good and well-coordinated, the majority reported that waiting lists were long and service provision was geographically variable, with no psychological services offering home visits which were required for those with mobility problems. A small study in Wales has also highlighted the lack of psychological support, particularly around the transition from RRMS to SPMS (Davies et al., 2015). The 'My MS My Needs' Survey by the MS Society (Redfern-Tofts, McDougal & McDougal, 2016) suggested that 21 per cent of people in the UK wanted more support for mood and emotional issues (ranging from 20 per cent in England to nearly 28 per cent in Wales). Thus, further work is needed to improve collaborative working and pathways and to improve staff skills (e.g., of mental health professionals) to meet the psychological needs of people with MS.

## ORGANISATIONS AND CHARITIES FOR MS

Third sector organisations which can provide information and support include: MS Society; MS Trust; MS-UK; MS National Therapy Centres; Action MS; Shift MS.

CHAPTER 6

# Implications for clinical practice

# Implications for clinical practice



## IMPACT OF DISEASE SEVERITY

Given the often cognitive-demanding nature of many of psychological interventions, most of the participants recruited for the abovementioned studies were more likely to be individuals at early disease stages, or affected by less severe variants (e.g., RRMS or limb-onset MND). As a consequence, the current literature on psychological approaches for people with HD, PD, MND, and MS and severe cognitive, communication, and physical impairments is even more limited. While guidance for specific severe presentations is available elsewhere (e.g., working with people with dementia; BPS, 2018), it is possible that some individuals with HD, PD, MND, and MS at a later stage and with a higher degree of impairment could still benefit from some of the approaches covered in this guidance, albeit with appropriate adaptations.

## MANUALISED APPROACHES VERSUS INDIVIDUALISED APPROACHES

### RECOMMENDATIONS

Manualised approaches will not always be appropriate and a formulation may suggest the need for a bespoke intervention. While not necessarily demonstrating changes on outcome measures, case studies and case series can give an indication of more individualised approaches. For example, for pwPD, EMDR was used with an individual with dementia and trauma (Ahmed et al., 2018), behavioural relaxation training and imagery reduced anxiety so that the client could have surgery (Lundervold et al., 2008), and behavioural relaxation training and self-focused exposure therapy helped two individuals with social anxiety and/or dyskinesia (Lundervold et al., 2013; Heinrichs et al., 2001). In addition, CBT reduced injection anxiety in a person with MS (Cox et al., 2004) as well as anxiety and depression in someone with HD (Silver, 2003). Sensory modulation and behaviour support reduced aggression in another individual with HD (Fisher & Brown, 2017), while hypnosis and CBT improved anxiety for a person with MS (Slatter, 2016) and hypnotic imagery and posthypnotic suggestion helped with pain for another client with the same condition (Dane et al., 1996). Finally, a case series adopting CBT showed reduced health anxiety for pwMS (Carrigan et al., 2018) and a further case series looked at remotivation therapy in HD (Sullivan et al., 2001). It is recommended therefore that all assessments lead to formulations from which the best combination of bespoke and manualised approaches can be adopted.

## ADAPTATIONS

### RECOMMENDATIONS

While some adherents to manualised approaches argue against adaptations, it is clear that these are important to consider for practitioners working with individuals with the conditions considered in this guidance. Some specific adjustments mentioned in CBT studies included shorter sessions, more repetition, simplified language and metaphors, and fewer writing tasks. While in some cases a high number of sessions was reported (e.g., 11–20 sessions for depression for pwMS), the length of CBT interventions has often been tailored around the characteristics of the target populations (e.g., fewer sessions for pwMND in light of the faster progression of the disease). Adaptions for mindfulness-based interventions

were similar, along with the omission or reduction of certain exercises involving particular motor or sensory components. Moreover, a pre-course mindfulness orientation session might be helpful, and booster sessions after the end of the course may also be required (Simpson et al., 2019).

While the focus in this guidance has been on the individuals with one of the four neurodegenerative conditions detailed above, several studies also included family members and carers in the interventions, particularly for pwMND. This may be another way of increasing accessibility and enabling effects of therapy to persist between and after sessions. Sometimes clients want partners involved, but equally sometimes they want the freedom to speak of difficulties alone (e.g., Weeks et al., 2019). Flexibility and transparent communication around this issue is clearly key.

Other adaptations to enhance accessibility might include considering the time of day; for example, older people might prefer the middle of the day, but younger people of working age with working age partners may only be able to access groups outside work.

Indeed, people may need different interventions at different stages of the disease course and it is likely that they will need additional support as the disease progresses. The Neurological Alliance consensus statement for mental health (The Neurological Alliance, 2019a) stipulates that such support should take into account both the neurological condition and mental health needs, and be tailored to individuals' specific requirements (e.g., in terms of communication and cognitive abilities).

## USE OF TECHNOLOGY

The use of technology in psychological interventions, especially following the outbreak of the COVID-19 pandemic in early 2020, is becoming increasingly more widespread. Telephone CBT, accessing mindfulness groups via video calling, and automated online CBT have all been trialled. As well as potentially reducing costs, these approaches may also facilitate access to treatment for some participants. However, they should not be seen as a panacea, since remote work (especially internet-based) may not be available or suitable for everyone. Furthermore, some people with MS found accessing computerised CBT too difficult due to cognitive difficulties and fatigue (e.g. Hind et al., 2010). Other studies also encountered some technological problems due to software glitches or poor internet connection which could detract from the intervention (e.g., Cavalera et al., 2018; Moss-Morris et al., 2012; van Kessel et al., 2016). One purely automated online CBT intervention for MS had very poor completion rates, which suggest that this approach may not be appropriate without some additional support (either via telephone or email) to enable people to complete the intervention (van Kessel et al., 2016). Another trial of computerised CBTi for pwPD also reported poor completion rates (Patel et al., 2017).

## ACCESS TO PSYCHOLOGICAL SERVICES

The Neurological Alliance, working in partnership with the BPS's Division of Neuropsychology and other patient organisations, has explored the mental health, emotional, and cognitive needs of people with neurological conditions living in England, including the conditions detailed in this guidance (The Neurological Alliance, 2017). In particular, the report highlights the complex interplay between neurological conditions and mental health, and why affected individuals may have specific needs in regards to improving mental health.

However, the Neurological Alliance's 2019 national neurology patient experience survey

in England also suggested that many people with neurological conditions are not receiving help with their mental health; 30 per cent of those who wanted it had not been referred or signposted to mental health support and 40 per cent said their needs were not being met at all regarding mental health (The Neurological Alliance, 2019b). Similarly, the All Party Parliamentary Group (APPG) for Parkinson's highlighted the difficulties for pwPD in accessing psychological help in all four nations (APPG for Parkinson's, 2018) and the 2016 My MS My Needs survey suggested that, while 23 per cent of pwMS had accessed support for mood and emotional difficulties, 21 per cent said they wanted more support (Redfern-Tofts et al., 2016)

The fact that many individuals are lacking support is perhaps not surprising, as the Neurological Alliance (2017) report concluded that current services have 'disjointed pathways, poorly coordinated care and variation across the country' (p.6). Even signposting to self-management or other information (e.g., that available from third sector organisations) can be poor. The report also found that access to mental health services can be denied when difficulties are seen to have an organic origin or, even when accessed, the staff do not have the relevant training to meet the person's needs. While this review has not assessed the importance of staff training – partly because of the lack of research in this area – its importance remains crucial. Training professionals working within the health and social care sector to develop the skills to signpost to relevant services, to understand the value of psychological approaches and, where appropriate, to offer psychological support or therapy has to be a priority. A recent survey (Barcroft, Simpson & Butchard, 2016) of psychologists (mostly clinical and neuropsychologists; $N = 149$) showed that around a third reported no specific teaching on individuals with conditions such as those in this guidance as part of their training, and a similar proportion reported having no related training in the last 12 months. Given that it might be expected, due to the extensive training of these professionals, that such teaching would be appropriately featured, it is disappointing to see that, even within the remit of clinical psychology, relevant training is not being provided.

To our knowledge, a detailed survey across neurological conditions similar to the one conducted by the Neurological Alliance in England (2017) has not been conducted in Scotland, Wales, or Northern Ireland. However, the Neurological Conditions Delivery Plan in Wales suggested that the coordination of care between services and agencies could 'appear fragmented and confusing' both for staff and for those with neurological conditions (NHS Wales, 2017, p.6). As noted in the BPS response document (BPS, 2019), the Neurological Conditions Draft Action Plan 2019 for Scotland (Scottish Government, 2018) contains very little mention of psychological functioning and mental health, suggesting it is not a priority.

The Neurological Alliance have suggested that, within the neuroscience pathway, there should be a 'psychological triage' to decide whose needs may be met by general mental health services and who may need a more specialist intervention (The Neurological Alliance, 2017, 2018). Service models would need to be flexible to allow for different modes of delivery to respond to cognitive and communication needs (e.g., groups may not always be appropriate and accessibility would need to be considered).

In addition, better care pathways are needed between mental health and neurology, and mental health services will need input from psychology and psychiatry professionals with appropriate expertise. More training and support for mental health workers, such as those in IAPT, has also been suggested so they can work with people with neurological conditions (The Neurological Alliance, 2018).

The review of the literature which informed this guidance indicated that, firstly, more research is needed across all conditions but in particular for individuals with HD, MND, and PD. However, the provision of psychological support can clearly not be delayed until more evidence is published and so, in the meantime, professionals must work with

the limited evidence and the more generic guidance currently available. Informal networks of interested practitioners (e.g., the Mental Health Hub recently set up by Parkinson's UK) are essential to form a multi-disciplinary supportive and educational environment to share current good practice. Evidence loses its potential without appropriate services being able to support its conclusions. We therefore hope that this guidance will both encourage the provision of high-quality evidence and support the development of effective, timely, and accessible psychological support for all people with Huntington's disease, Parkinson's, motor neurone disease, and multiple sclerosis.

# REFERENCES

# References


Abolghasemi, A., Taherifard, M., Farhang, S., Kiamarsi, A. & Saharkhiz A.A. (2016). The effect of supportive-expressive therapy on hope and quality of life in patients with multiple sclerosis (MS). *Archives of Psychiatry and Psychotherapy*, *18*(4), 20–27. https://doi.org/10.12740/app/64975

A'Campo, L.E.I., Spliethoff-Kamminga, N.G.A. & Roos, R.A.C. (2012). The Patient Education Program for Huntington's Disease (PEP-HD). *Journal of Huntington's Disease*, *1*(1), 47–56. https://doi.org/10.3233/JHD-2012-120002

Abrahams, S. (2013). ALS, cognition and the clinic. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *14*(1), 3–5. https://doi.org/10.3109/21678421.2013.760149

Advocat, J., Enticott, J., Vandenberg, B., Hassed, C., Hester, J. & Russell, G. (2016). The effects of a mindfulness-based lifestyle program for adults with Parkinson's disease: A mixed methods, wait list controlled randomised control study. *BMC Neurology, 16*(166). https://doi.org/10.1186/s12883-016-0685-1

Agland, S., Lydon, A., Shaw, S., Lea, R., Mortimer-Jones, S. & Lechner-Scott, J. (2018). Can a stress management programme reduce stress and improve quality of life in people diagnosed with multiple sclerosis? *Multiple Sclerosis Journal – Experimental, Translational and Clinical*, *4*(4), 2055217318813179. https://doi.org/10.1177/2055217318813179

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (5th ed.).* Arlington, VA: American Psychiatric Publishing.

Andersen, P.M., Abrahams, S., Borasio, G.D., de Carvalho, M., Chio, A., Van Damme, P., … Weber, M. (2012). EFNS guidelines on the Clinical Management of Amyotrophic Lateral Sclerosis (MALS) – revised report of an EFNS task force. *European Journal of Neurology*, *19*(3), 360–375. https://doi.org/10.1111/j.1468-1331.2011.03501.x

Anderson, K.E., Van Duijn, E., Craufurd, D., Drazinic, C., Edmondson, M., Goodman, N., … Goodman, L.V. V. (2018). Clinical management of neuropsychiatric symptoms of Huntington disease: Expert-based consensus guidelines on agitation, anxiety, apathy, psychosis and sleep disorders. *Journal of Huntington's Disease*, *7*(4), 355–366. https://doi.org/10.3233/JHD-180293

Anderson, J.K., Turner, A. & Clyne, W. (2017). Development and feasibility of the Help to Overcome Problems Effectively (HOPE) self-management intervention for people living with multiple sclerosis. *Disability and Rehabilitation 39*(11), 1114–1121. https://doi.org/10.1080/09638288.2016.1181211

Aoun, S.M., Chochinov, H.M. & Kristjanson, L.J. (2015). Dignity therapy for people with motor neurone disease and their family caregivers: A feasibility study. *Journal of Palliative Medicine*, *18*(1), 31–37. https://doi.org/10.1089/jpm.2014.0213

APPG for Parkinson's. (2018). *Mental health matters too: Improving mental health services for people with Parkinson's who experience anxiety and depression.* Retrieved from https://www.parkinsons.org.uk/sites/default/files/2018-05/APPG on Parkinson%27s mental health report – May 2018.pdf

Bachoud-Lévi, A.C., Ferreira, J., Massart, R., Youssov, K., Rosser, A., Busse, M., … Burgunder, J.M. (2019). International guidelines for the treatment of Huntington's disease. *Frontiers in Neurology*, *10*(JUL), 1–18. https://doi.org/10.3389/fneur.2019.00710

Banaszkiewicz, K., Sitek, E.J., Rudzinska, M., Sołtan, W., Sławek, J. & Szczudlik, A. (2012). Huntington's disease from the patient, caregiver and physician's perspectives: Three sides of the same coin? *Journal of Neural Transmission (Vienna, Austria, 1996), 119*(11), 1361–1365. https://doi.org/10.1007/s00702-012-0787-x

Barbosa, E.R. (2013). Non-motor symptoms in Parkinson's disease. *Arquivos de Neuro-Psiquiatria, 71*(4), 203–204. https://doi.org/10.1590/0004-282X20130001

Barcroft, R., Simpson, J. & Butchard, S. (2016). Support for practitioners working with people with neurodegenerative disorders. *The FPOP Bulletin, 136*, 21–28.

Barker-Collo, S., Cartwright, C. & Read, J. (2006). Into the unknown: The experiences of individuals living with multiple sclerosis. *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses, 38*(6), 435–441, 446.

Barlow, J., Turner, A., Edwards, R. & Gilchrist, M. (2009). A randomised controlled trial of lay-led self-management for people with multiple sclerosis. *Patient Education and Counseling, 77*(1), 81–89. https://doi.org/10.1016/j.pec.2009.02.009

Bates, G.P., Tabrizi, S.J. & Jones, L. (2014). *Huntington's Disease.* (4th edn. G. P. Bates, S. J. Tabrizi & L. Jones, Eds.). New York: Oxford University Press.

Bender, M. & Wainwright, T. (2005). The need for psychotherapeutic services for people with Parkinson's disease. *Psychologist's Special Interest Group Working With Older People Newsletter, 89*, 17–23.

Berardelli, I., Bloise, M.C., Bologna, M., Conte, A., Pompili, M., Lamis, D.A., … Fabbrini, G. (2018). Cognitive behavioral group therapy versus psychoeducational intervention in Parkinson's disease. *Neuropsychiatric Disease and Treatment, 14*, 399–405. https://doi.org/10.2147/NDT.S152221

Boeschoten, R.E., Braamse, A.M.J., Beekman, A.T.F., Cuijpers, P., van Oppen, P., Dekker, J. & Uitdehaag, B.M.J. (2017). Prevalence of depression and anxiety in Multiple Sclerosis: A systematic review and meta-analysis. *Journal of the Neurological Sciences*, *372*, 331–341. https://doi.org/10.1016/j.jns.2016.11.067

Bombard, Y., Palin, J., Friedman, J.M., Veenstra, G., Creighton, S., Paulsen, J.S., … Hayden, M.R. (2011). Factors associated with experiences of genetic discrimination among individuals at risk for Huntington disease. *American Journal of Medical Genetics. Part B, Neuropsychiatric Genetics: The Official Publication of the International Society of Psychiatric Genetics*, *156B*(1), 19–27. https://doi.org/10.1002/ajmg.b.31130

BPS (2018). *Psychological dimensions of dementia.* Retrieved from https://www.bps.org.uk/news-and-policy/psychological-dimensions-dementia

BPS (2019). British Psychological Society response to the Scottish Government Neurological conditions national action plan 2019–2024: draft for consultation, (February), 1–14.

BPS Professional Practice Board (2009). *Psychological services for people with Parkinson's disease*. Leicester: Author.

Brands, I., Bol, Y., Stapert, S., Köhler, S. & van Heugten, C. (2018). Is the effect of coping styles disease specific? Relationships with emotional distress and quality of life in acquired brain injury and multiple sclerosis. *Clinical Rehabilitation*, *32*(1), 116–126. https://doi.org/10.1177/0269215517718367

Broadstock, M., Michie, S. & Marteau, T. (2000). Psychological consequences of predictive genetic testing: A systematic review. *European Journal of Human Genetics: EJHG*, *8*(10), 731–738. https://doi.org/10.1038/sj.ejhg.5200532

Brown, R. & Jahanshahi, M. (1995). Depression in Parkinson's disease: A psychosocial viewpoint. *Advances in Neurology*, *65*, 61–84.

Brownlee, W.J., Hardy, T.A., Fazekas, F. & Miller, D.H. (2017). Diagnosis of multiple sclerosis: Progress and challenges. *The Lancet*, *389*(10076), 1336–1346. https://doi.org/10.1016/S0140-6736(16)30959-X

Butterfield, L.C., Cimino, C.R., Salazar, R., Sanchez-Ramos, J., Bowers, D. & Okun, M.S. (2017). The Parkinson's Active Living (PAL) Program. *Journal of Geriatric Psychiatry and Neurology*, *30*(1), 11–25. https://doi.org/10.1177/0891988716673467

Calandri, E., Graziano, F., Borghi, M. & Bonino, S. (2017). Improving the quality of life and psychological well-being of recently diagnosed multiple sclerosis patients: Preliminary evaluation of a group-based cognitive behavioral intervention. *Disability and Rehabilitation*, *39*(15), 1474–1481. https://doi.org/10.1080/09638288.2016.1198430

Calleo, J.S., Amspoker, A.B., Sarwar, A.I., Kunik, M.E., Jankovic, J., Marsh, L., York, M., Stanley, M.A. (2015). A pilot study of a cognitive-behavioral treatment for anxiety and depression in patients with Parkinson disease. *Journal of Geriatric Psychiatry and Neurology, 28*, 210–217. https://doi.org/10.1177/0891988715588831

Canter, A.H. (1951). MMPI profiles in multiple sclerosis. *Journal of Consulting Psychology*, *15*(3), 253–256. https://doi.org/10.1037/h0057864

Carletto, S., Borghi, M., Bertino, G., Oliva, F., Cavallo, M., Hofmann, A., … Ostacoli, L. (2016). Treating post-traumatic stress disorder in patients with multiple sclerosis: A randomized controlled trial comparing the efficacy of eye movement desensitization and reprocessing and relaxation therapy. *Frontiers in Psychology*, *7*, 526. https://doi.org/10.3389/fpsyg.2016.00526

Cash, T.V., Ekouevi, V.S., Kilbourn, C., Lageman, S.K. (2015). Pilot study of a mindfulness-based group intervention for individuals with Parkinson's disease and their caregivers. *Mindfulness, 7,* 361–371. https://doi.org/10.1007/s12671-015-0452-1

Cavalera, C., Rovaris, M., Mendozzi, L., Pugnetti, L., Garegnani, M., Castelnuovo, G., … Pagnini, F. (2018). Online meditation training for people with multiple sclerosis: A randomized controlled trial. *Multiple Sclerosis Journal*, 1352458518761187. https://doi.org/10.1177/1352458518761187

Ceravolo, R., Frosini, D., Rossi, C. & Bonuccelli, U. (2010). Spectrum of addictions in Parkinson's disease: From dopamine dysregulation syndrome to impulse control disorders. *Journal of Neurology*, *257*(SUPPL. 2), 276–283. https://doi.org/10.1007/s00415-010-5715-0

Charcot, J. (1877). *Lectures on diseases of the nervous system*. London: New Sydenham Society.

Chaudhuri, K.R & Schapira, A.H. (2009). Non-motor symptoms of Parkinson's disease: Dopaminergic pathophysiology and treatment. *The Lancet Neurology*, *8*(5), 464–474. https://doi.org/10.1016/S1474-4422(09)70068-7

Chaudhuri, K.R. & Schapira, A.H.V. (2006). Non-motor symptoms of PD diagnosis and management. *The Lancet Neurology*, *5*(March), 235–245. https://doi.org/10.1016/s1474-4422(06)70373-8

Chiò, A., Logroscino, G., Hardiman, O., Swingler, R., Mitchell, D., Beghi, E. & Traynor, B.G. (2009). Prognostic factors in ALS: A critical review. *Amyotrophic Lateral Sclerosis*, *10*(5–6), 310–323. https://doi.org/10.3109/17482960802566824

Chisholm, L.Z., Flavin, K.T., Paulsen, J.S. & Ready, R. (2013). Psychological well-being in persons affected by Huntington's disease: A comparison of at-risk, prodromal, and symptomatic groups. *Journal of Health Psychology*, *18*(3), 408–418. https://doi.org/10.1177/1359105312444646

Chwastiak, L., Ehde, D.M., Gibbons, L.E., Sullivan, M., Bowen, J.D. & Kraft, G.H. (2002). Depressive symptoms and severity of illness in multiple sclerosis: Epidemiologic study of a large community sample. *American Journal of Psychiatry*, *159*(11), 1862–1868. https://doi.org/10.1176/appi.ajp.159.11.1862

Crozier, S., Robertson, N. & Dale, M. (2014). The psychological impact of predictive genetic testing for Huntington's disease: A systematic review of the literature. *Journal of Genetic Counseling*, *24*(1), 29–39. https://doi.org/10.1007/s10897-014-9755-y

Dale, M. & van Duijn, E. (2015). Anxiety in Huntington's disease. *Journal of Neuropsychiatry and*

*Clinical Neurosciences*, *27*(4), 262–271. https://doi.org/10.1176/appi.neuropsych.14100265

Davies, F., Edwards, A., Brain, K., Edwards, M., Jones, R., Wallbank, R., … Wood, F. (2015). You are just left to get on with it: Qualitative study of patient and carer experiences of the transition to secondary progressive multiple sclerosis. *BMJ Open*, *5*(7). https://doi.org/10.1136/bmjopen-2015-007674

Dennison, L., Moss-Morris, R. & Chalder, T. (2009). A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clinical Psychology Review*, *29*(2), 141–153. https://doi.org/10.1016/j.cpr.2008.12.001

Diane Redfern-Tofts, L., McDougal, A. & McDougal, W. (2016). *My MS My Needs 2016: Access to treatment and health care*. Available from: www.bl.uk/collection-items/my-ms-my-needs-2016-access-to-treatment-and-health-care-technical-report#

Dickson, S., Barbour, R.S., Brady, M., Clark, A.M. & Paton, G. (2008). Patients' experiences of disruptions associated with post-stroke dysarthria. *International Journal of Language and Communication Disorders*, *43*(2), 135–153. https://doi.org/10.1080/13682820701862228

Dissanayaka, N.N., Idu Jion, F., Pachana, N.A., O'Sullivan, J.D., Marsh, R., Byrne, G.J. & Harnett, P. (2016). Mindfulness for Motor and Nonmotor Dysfunctions in Parkinson's Disease. *Parkinson's disease, 2016,* 7109052. https://doi.org/10.1155/2016/7109052

Dobkin, R.D., Menza, M., Allen, L.A., Gara, M.A., Mark, M.H., Tiu, J., Bienfait, K.L. & Friedman, J.(2011). Cognitive-behavioral therapy for depression in Parkinson's disease: A randomized, controlled trial. *American Journal of Psychiatry, 168,* 1066–1074. https://doi.org/10.1176/appi.ajp.2011.10111669

Dobkin, R.D., Mann, S.L., Gara, M.A., Interian, A., Rodriguez, K.M. & Menza, M. (2020). Telephone-based cognitive behavioral therapy for depression in Parkinson disease: A randomized controlled trial. *Neurology, 94*(16) E1764–E1773. https://doi.org/10.1212/WNL.0000000000009292

Duisterhof, M. & Trijsburg, R. (2001). Psychological studies in Huntington's disease: Making up the balance. *Journal of Medical Genetics,* 852–861. https://dx.doi.org/10.1136%2Fjmg.38.12.852

Dumas, E.M., van den Bogaard, S.J., Middelkoop, H.A. & Roos, R.A. (2013). A review of cognition in Huntington's disease. *Frontiers in bioscience (Scholar edition), 5,* 1–18. https://doi.org/10.2741/s355

Dwason, S., Kristjanson, L., Toye, C.M. & Flett, P. (2004). Living with Huntington's disease: Need for supportive care. *Nursing and Health Sciences*, *6*(2), 123–130. https://doi.org/10.1111/j.1442-2018.2004.00183.x

Edwards, R.G., Barlow, J.H. & Turner, A.P. (2008). Experiences of diagnosis and treatment among people with multiple sclerosis. *Journal of Evaluation in Clinical Practice*, *14*(3), 460–464. https://doi.org/10.1111/j.1365-2753.2007.00902.x

Ehde, D.M., Elzea, J.L., Verrall, A.M., Gibbons, L.E., Smith, A.E. & Amtmann, D. (2015). Efficacy of a telephone-delivered self-management intervention for persons with multiple sclerosis: A randomized controlled trial with a one-year follow-up. *Archives of Physical Medicine and Rehabilitation 96*(11), 1945–58 e2. https://doi.org/10.1016/j.apmr.2015.07.015

Emre, M., Aarsland, D., Brown, R., Burn, D.J., Duyckaerts, C., Mizuno, Y., … Dubois, B. (2007). Clinical diagnostic criteria for dementia associated with Parkinson's disease. *Movement Disorders*, *22*(12), 1689–1707. https://doi.org/10.1002/mds.21507

Evans, D. (2003). Hierarchy of evidence: A framework for ranking evidence evaluating healthcare interventions. *Journal of Clinical Nursing*, *12*(1), 77–84. https://doi.org/10.1046/j.1365-2702.2003.00662.x

Evans, S.J.W., Douglas, I., Rawlins, M.D., Wexler, N. S., Tabrizi, S.J. & Smeeth, L. (2013). Prevalence of adult Huntington's disease in the UK based on diagnoses recorded in general practice records. *Journal of Neurology, Neurosurgery, and Psychiatry*, *84*(10), 1156–1160. https://doi.org/10.1136/jnnp-2012-304636

Even, C. & Weintraub, D. (2012). Is depression in Parkinson's disease (PD) a specific entity? *Journal of Affective Disorders*, *139*(2), 103–112. https://doi.org/10.1016/j.jad.2011.07.002

Fischer, A., Schroder, J., Vettorazzi, E., Wolf, O.T., Pottgen, J., Lau, S., … Fischer, A. (2015). An online programme to reduce depression in patients with multiple sclerosis: A randomised controlled trial. *The Lancet Psychiatry*, *2*(3), 217–223. https://doi.org/10.1016/s2215-0366(14)00049-2

Feicke, J., Spörhase, U., Köhler, J., Busch, C. & Wirtz, M. (2014). A multicenter, prospective, quasi-experimental evaluation study of a patient education program to foster multiple sclerosis self-management competencies. *Patient Education and Counseling*, *97*(3), 361–369. https://doi.org/10.1016/j.pec.2014.09.005

Feinstein, A., Magalhaes, S., Richard, J.F., Audet, B. & Moore, C. (2014). The link between multiple sclerosis and depression. *Nature Reviews Neurology*, *10*(9), 507–517. https://doi.org/10.1038/nrneurol.2014.139

Foley, G., Timonen, V. & Hardiman, O. (2014). Understanding psycho-social processes underpinning engagement with services in motor neurone disease: A qualitative study. *Palliative Medicine*, *28*(4), 318–325. https://doi.org/10.1177/0269216313512013

Folstein, S. (1989). *Huntington's disease: A disorder of families*. Maryland: The Johns Hopkins University Press.

Foltynie, T., Brayne, C.E.G., Robbins, T.W. & Barker, R.A. (2004). The cognitive ability of an incident cohort of Parkinson's patients in the UK. The CamPaIGN study. *Brain*, *127*(3), 550–560. https://doi.org/10.1093/brain/awh067

Forman, A.C. & Lincoln, N.B. (2010). Evaluation of an adjustment group for people with multiple sclerosis: a pilot randomized controlled trial. *Clin Rehabil*, *24*(3), 211–221. https://doi.org/10.1177/0269215509343492

Forrest Keenan, K., van Teijlingen, E., McKee, L., Miedzybrodzka, Z., Simpson, S. a, Keenan, K. F., … Simpson, S. a. (2009). How young

people find out about their family history of Huntington's disease. *Social Science & Medicine (1982)*, *68*(10), 1892–1900. https://doi.org/10.1016/j.socscimed.2009.02.049

Garlovsky, J.K., Overton, P.G. & Simpson, J. (2016). Psychological predictors of anxiety and depression in Parkinson's disease: A systematic review. *Journal of Clinical Psychology*, *72*(10), 979–998. https://doi.org/10.1002/jclp.22308

Genet, J.J. & Siemer, M. (2011). Flexible control in processing affective and non-affective material predicts individual differences in trait resilience. *Cognition and Emotion*, *25*(2), 380–388. https://doi.org/10.1080/02699931.2010.491647

Gilbertson, R.M. & Klatt, M.D. (2017). Mindfulness in motion for people with multiple sclerosis: A feasibility study. *International Journal of MS Care*, *19*(5), 225–231. https://doi.org/10.7224/1537-2073.2015-095

Gillions, A., Cheang, R. & Duarte, R. (2019). The effect of mindfulness practice on aggression and violence levels in adults: A systematic review. *Aggression and Violent Behavior, 48,* 104-115. doi:10.1016/j.avb.2019.08.012

Golbe, L.I. (1991). Young-onset parkinson's disease: A clinical review. *Neurology*, *41*(2), 168–173. https://doi.org/10.1212/wnl.41.2_part_1.168

Goldenberg M. M. (2012). Multiple sclerosis review. *P & T: A peer-reviewed journal for formulary management, 37*(3), 175–184.

Goldman, J.G. & Holden, S. (2014). Treatment of psychosis and dementia in Parkinson's disease. *Current Treatment Options in Neurology*, *16*(3), 1–25. https://doi.org/10.1007/s11940-013-0281-2

Goldstein, L.H., Atkins, L., Landau, S., Brown, R.G. & Leigh, P.N. (2006). Longitudinal predictors of psychological distress and self-esteem in people with ALS. *Neurology*, *67*(9), 1652–1658. https://doi.org/10.1212/01.wnl.0000242886.91786.47

Gould, R.L., Coulson, M.C., Brown, R.G., Goldstein, L.H., Al-Chalabi, A., Howard, R.J., … Coulson, M. C. (2015). Psychotherapy and pharmacotherapy interventions to reduce distress or improve well-being in people with amyotrophic lateral sclerosis: A systematic review. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *16*(5–6), 293–302. https://doi.org/10.3109/21678421.2015.1062515

Graziano, F., Calandri, E., Borghi, M. & Bonino, S. (2014). The effects of a group-based cognitive behavioral therapy on people with multiple sclerosis: A randomized controlled trial. *Clinical Rehabilitation*, *28*(3), 264–274. https://doi.org/10.1177/0269215513501525

Greenwood, D.I. (2013). Nutrition management of amyotrophic lateral sclerosis. *Nutrition in Clinical Practice*, *28*(3), 392–399. https://doi.org/10.1177/0884533613476554

Grossman, P., Kappos, L., Gensicke, H., D'Souza, M., Mohr, D.C., Penner, I.K. & Steiner, C. (2010). MS quality of life, depression, and fatigue improve after mindfulness training: A randomized trial. *Neurology*, *75*(13), 1141–1149. https://doi.org/10.1212/WNL.0b013e3181f4d80d

Hadinia, A., Meyer, A., Bruegger, V., Hatz, F., Nowak, K., Taub, E., Nyberg, E., Stieglitz, R.D., Fuhr, P., Gschwandtner, U. (2016). Cognitive behavioral group therapy reduces stress and improves the quality of life in patients with Parkinson's disease. *Frontiers in Psychology, 7,* 1975. https://doi.org/10.3389/fpsyg.2016.01975

Hagberg, A., Bui, T.-H. & Winnberg, E. (2011). More appreciation of life or regretting the test? Experiences of living as a mutation carrier of Huntington's disease. *Journal of Genetic Counseling*, *20*(1), 70–79. https://doi.org/10.1007/s10897-010-9329-6

Hamel, D.L., Deloire, M., Ruet, A., Charré-Morin, J., Saubusse, A., Ouallet, J.C. & Brochet, B. (2015). Deciphering depressive mood in relapsing-remitting and progressive multiple sclerosis and its consequence on quality of life. *PLoS ONE*, *10*(11), 1–12. https://doi.org/10.1371/journal.pone.0142152

Hardiman, O., Al-Chalabi, A., Chio, A., Corr, E.M., Logroscino, G., Robberecht, W., … Van Den Berg, L.H. (2017). Amyotrophic lateral sclerosis. *Nature Reviews Disease Primers*, *3*, 1–19. https://doi.org/10.1038/nrdp.2017.71

Harper, P., Lim, C. & Craufurd, D. (2000). Ten years of presymptomatic testing for Huntington's disease: the experience of the UK Huntington's Disease Prediction Consortium. *Journal of Medical Genetics*, 567–571. https://doi.org/10.1136/jmg.37.8.567

Harrison, A.M., Bogosian, A., Silber, E., McCracken, L.M. & Moss-Morris, R. (2015). It feels like someone is hammering my feet: Understanding pain and its management from the perspective of people with multiple sclerosis. *Multiple Sclerosis Journal*, *21*(4), 466–476. https://doi.org/10.1177/1352458514544538

Healthcare Improvement Scotland (2019). *General Standards for Neurological Care and Support*. Retrieved from www.healthcareimprovementscotland.org

Hecht, M., Hillemacher, T., Gräsel, E., Tigges, S., Winterholler, M., Heuss, D., … Neundörfer, B. (2002). Subjective experience and coping in ALS. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders*, *3*(4), 225–232. https://doi.org/10.1080/146608202760839009

Hemmati Maslakpak, M. & Raiesi, Z. (2014). Effect of a self-management and follow-up program on self-efficacy in patients with multiple sclerosis: a randomized clinical trial. *Nursing and Midwifery Studies*, *3*(4), e25661. https://doi.org/10.17795/nmsjournal25661

Hillemacher, T., Graäßel, E., Tigges, S., Bleich, S., Neundörfer, B., Kornhuber, J. & Hecht, M.J. (2004). Depression and bulbar involvement in amyotrophic lateral sclerosis. *Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders*, *5*(4), 245–249. https://doi.org/10.1080/14660820410021294

Ho, A. & Hocaoglu, M. (2011). Impact of Huntington's across the entire disease spectrum: The phases and stages of disease from the patient

perspective. *Clinical Genetics*, *80*(3), 235–239. https://doi.org/10.1111/j.1399-0004.2011.01748.x

Hoang, H., Laursen, B., Stenager, E.N. & Stenager, E. (2016). Psychiatric co-morbidity in multiple sclerosis: The risk of depression and anxiety before and after MS diagnosis. *Multiple Sclerosis Journal*, *22*(3), 347–353. https://doi.org/10.1177/1352458515588973

Hobson, E.V. & McDermott, C.J. (2016). Supportive and symptomatic management of amyotrophic lateral sclerosis. *Nature Reviews Neurology*, *12*(9), 526–538. https://doi.org/10.1038/nrneurol.2016.111

Hogg, K.E., Goldstein, L.H. & Leigh, P.N. (1994). The psychological impact of motor neurone disease. *Psychological Medicine*, *24*(3), 625–632. https://doi.org/10.1017/S003329170002777X

Hoogerwerf, A.E.W., Bol, Y., Lobbestael, J., Hupperts, R. & Van Heugten, C.M. (2017). Mindfulness-based cognitive therapy for severely fatigued multiple sclerosis patients: A waiting list controlled study. *Journal of Rehabilitation Medicine*, *49*(6), 497–504. https://doi.org/10.2340/16501977-223

Horne-Thompson, A. & Bolger, K. (2010). An investigation comparing the effectiveness of a live music therapy session and recorded music in reducing anxiety for patients with amyotrophic lateral sclerosis/ motor neurone disease. *Australian Journal of Music Therapy*, *21*, 23–38.

Hubers, a.a.M., Reedeker, N., Giltay, E.J., Roos, R.a.C., van Duijn, E. & van der Mast, R.C. (2012). Suicidality in Huntington's disease. *Journal of Affective Disorders*, *136*(3), 550–557. https://doi.org/10.1016/j.jad.2011.10.031

Irvine, H., Davidson, C., Hoy, K. & Lowe-Strong, A. (2009). Psychosocial adjustment to multiple sclerosis: Exploration of identity redefinition. *Disability and Rehabilitation*, *31*(8), 599–606. https://doi.org/10.1080/09638280802243286

Janssens, A.C.J.W., Van Doorn, P.A., De Boer, J.B., Kalkers, N.F., Van Der Merché, F.G.A., Passchier, J. & Hintzen, R.Q. (2003). Anxiety and depression influence the relation between disability status and quality of life in multiple sclerosis. *Multiple Sclerosis*, *9*(4), 397–403. https://doi.org/10.1191/1352458503ms930oa

Janvin, C., Aarsland, D., Larsen, J.P. & Hugdahl, K. (2003). Neuropsychological profile of patients with Parkinson's disease without dementia. *Dementia and Geriatric Cognitive Disorders*, *15*(3), 126–131. https://doi.org/10.1159/000068483

Jensen, M.P., Ehde, D.M., Gertz, K.J., Stoelb, B.L., Dillworth, T.M., Hirsh, A.T., … Kraft, G.H. (2011). Effects of self-hypnosis training and cognitive restructuring on daily pain intensity and catastrophizing in individuals with multiple sclerosis and chronic pain. *International Journal of Clinical and Experimental Hypnosis*, *59*(1), 45–63. https://doi.org/10.1080/00207144.2011.522892

Jiménez-Murcia, S., Bove, F.I., Israel, M., Steiger, H., Fernández-Aranda, F., Álvarez-Moya, E., … Menchon, J.M. (2012). Cognitive-behavioral therapy for pathological gambling in Parkinson's disease: A pilot controlled study. *European Addiction Research*, *18*(6), 265–274. https://doi.org/10.1159/000337442

Johnson, J., Leigh, P.N., Shaw, C.E., Ellis, C., Burman, R. & Al-Chalabi, A. (2012). Eating-derived pleasure in amyotrophic lateral sclerosis as a predictor of non-oral feeding. *Amyotrophic Lateral Sclerosis*, *13*(6), 555–559. https://doi.org/10.3109/17482968.2012.704925

Kalia, L.V & Lang, A.E. (2015). Parkinson's disease. *Lancet*, *24*(1), 92–98. https://doi.org/10.1016/S0140-6736(14)61393-3

van Kessel, K, Moss-Morris, R., Willoughby, E., Chalder, T., Johnson, M.H. & Robinson, E. (2008). A randomized controlled trial of cognitive behavior therapy for multiple sclerosis fatigue. *Psychosomatic Medicine*, *70*(2), 205–213. https://doi.org/10.1097/psy.0b013e3181643065

Kingwell, E., Marriott, J.J., Jetté, N., Pringsheim, T., Makhani, N., Morrow, S.A., … Marrie, R.A. (2013). Incidence and prevalence of multiple sclerosis in Europe: A systematic review. *BMC Neurology*, *13*. https://doi.org/10.1186/1471-2377-13-128

Kiropoulos, L.A., Kilpatrick, T., Holmes, A. & Threader, J. (2016). A pilot randomized controlled trial of a tailored cognitive behavioural therapy based intervention for depressive symptoms in those newly diagnosed with multiple sclerosis. *BMC Psychiatry*, *16*(1), 435. https://doi.org/10.1186/s12888-016-1152-7

Kolahkaj, B. & Zargar, F. (2015). Effect of mindfulness-based stress reduction on anxiety, depression and stress in women with multiple sclerosis. *Nursing and Midwifery Studies*, *4*(4), e29655. https://doi.org/10.17795/nmsjournal29655

Kraepelien, M., Schibbye, R., Månsson, K., Sundström, C., Riggare, S., Andersson, G., Lindefors, N., Svenningsson, P., Kaldo, V. (2020). Individually tailored internet-based cognitive-behavioral therapy for daily functioning in patients with Parkinson's disease: A randomized controlled trial. *Journal of Parkinson's Disease,10,* 653–664. https://doi.org/10.3233/jpd-191894

Kwok, J.Y.Y.Y., Kwan, J.C.Y.Y., Auyeung, M., Mok, V.C.T.T., Lau, C.K.Y.Y., Choi, K.C. & Chan, H.Y.L.L. (2019). Effects of mindfulness yoga vs stretching and resistance training exercises on anxiety and depression for people with Parkinson disease: A randomized clinical trial. *JAMA Neurology*, *1*(76), 755–763. https://doi.org/10.1001/jamaneurol.2019.0534

Labuschagne, I., Jones, R., Callaghan, J., Whitehead, D., Dumas, E.M., Say, M.J., … Stout, J.C. (2013). Emotional face recognition deficits and medication effects in pre-manifest through stage-II Huntington's disease. *Psychiatry Research*, *207*(1–2), 118–126. https://doi.org/10.1016/j.psychres.2012.09.022

Laccone, F., Engel, U., Holinski-Feder, E., Weigell-Weber, M., Marczinek, K., Nolte, D., … Riess, O. (1999). DNA analysis of Huntington's disease: five years of experience in Germany, Austria, and Switzerland. *Neurology*, *53*(4), 801–806.https://doi.org/10.1212/wnl.53.4.801

Langenmayr, A, & Schöttes, N.. (2000). Psychotherapy with Multiple-Sclerosis Patients. *Psychological Reports, 86*(2), 495–508. https://doi.org/10.2466/pr0.2000.86.2.495

Langgartner, M., Langgartner, I., & Drlicek, M. (2005). The patient's journey: multiple sclerosis. *BMJ (Clinical research edn.), 330*(7496), 885–888. https://doi.org/10.1136/bmj.330.7496.885

Larcombeand, N., Wilson, P.H., Larcombe, N.A. & Wilson, P.H. (1984). An evaluation of cognitive-behaviour therapy for depression in patients with multiple sclerosis. *British Journal of Psychiatry*, *145*, 366–371. https://doi.org/10.1192/bjp.145.4.366

Leclaire, K., Cecil, A., LaRussa, A., Stuart, F., Hemond, C.C., Healy, B.C., … Glanz, B.I. (2018). Short report: A pilot study of a group positive psychology intervention for patients with multiple sclerosis. *International Journal of MS Care*, *20*(3), 136–141. https://doi.org/10.7224/1537-2073.2017-002

Lee, A.H. & Digiuseppe, R. (2018). Anger and aggression treatments: A review of meta-analyses. *Current Opinion in Psychology, 19,* 65–74. doi:10.1016/j.copsyc.2017.04.004

Lee, J.N., Rigby, S.A., Burchardt, F., Thornton, E.W., Dougan, C. & Young, C.A. (2001). Quality of life issues in motor neurone disease: The development and validation of a coping strategies questionnaire, the MND Coping Scale. *Journal of the Neurological Sciences*, *191*(1–2), 79–85. https://doi.org/10.1016/S0022-510X(01)00619-0

Leng, T.R., Woodward, M.J., Stokes, M.J., Swan, A.V., Wareing, L.A. & Baker, R. (2003). Effects of multisensory stimulation in people with Huntington's disease: A randomized controlled pilot study. *Clinical Rehabilitation*, *17*(1), 30–41. https://doi.org/10.1191/0269215503cr582oa

Leroi, I., Ahearn, D.J., Andrews, M., Mcdonald, K.R., Byrne, E.J. & Burns, A. (2011). Behavioural disorders, disability and quality of life in Parkinson's disease. *Age and Ageing*, *40*(5), 614–621. https://doi.org/10.1093/ageing/afr078

Lillo, P., Savage, S., Mioshi, E., Kiernan, M.C. & Hodges, J.R. (2012). Amyotrophic lateral sclerosis and frontotemporal dementia: A behavioural and cognitive continuum. *Amyotrophic Lateral Sclerosis*, *13*(1), 102–109. https://doi.org/10.3109/17482968.2011.639376

Lincoln, N.B., Yuill, F., Holmes, J., Drummond, A.E., Constantinescu, C.S., Armstrong, S. & Phillips, C. (2011). Evaluation of an adjustment group for people with multiple sclerosis and low mood: A randomized controlled trial. *Multiple Sclerosis Journal*, *17*(10), 1250–1257. https://doi.org/10.1177/1352458511408753

Litvan, I., Goldman, J.G., Tröster, A.I., Schmand, B.A., Weintraub, D., Petersen, R.C., … Emre, M. (2012). Diagnostic criteria for mild cognitive impairment in Parkinson's disease: Movement Disorder Society Task Force guidelines. *Movement Disorders*, *27*(3), 349–356. https://doi.org/10.1002/mds.24893

Logroscino, G., Traynor, B.J., Hardiman, O., Chió, A., Mitchell, D., Swingler, R.J., … Beghi, E. (2010). Incidence of amyotrophic lateral sclerosis in Europe. *Journal of Neurology, Neurosurgery and Psychiatry*, *81*(4), 385–390. https://doi.org/10.1136/jnnp.2009.183525

Loma, I., & Heyman, R. (2011). Multiple sclerosis: pathogenesis and treatment. *Current Neuropharmacology, 9*(3), 409–416. https://doi.org/10.2174/157015911796557911

Lublin, F.D. (2014). New multiple sclerosis phenotypic classification. *European Neurology*, *72*(suppl 1), 1–5. https://doi.org/10.1159/000367614

Lublin, F.D., Reingold, S.C., Cohen, J.A., Cutter, G.R., Thompson, A.J., Wolinsky, J.S., … Sormani, M.P. (2014). Defining the clinical course of multiple sclerosis. *Neurology*, *83*, 278–286. https://doi.org/10.1212/wnl.0000000000000560

Maes, S., Leventhal, H. & de Ridder, D.T.D. (1996). Coping with chronic diseases. In M. Zeidner & S. Endler, N (Eds.), *Handbook of coping: Theory, research, applications* (pp. 221–251). Oxford, England: John Wiley & Sons.

Marin, B., Boumé diene, F., Logroscino, G., Couratier, P., Babron, M.C., Leutenegger, A.L., … Beghi, E. (2017). Variation in world wide incidence of amyotrophic lateral sclerosis: A meta-analysis. *International Journal of Epidemiology*, *46*(1), 57–74. https://doi.org/10.1093/ije/dyw061

Mark, M. (2006). Pathogenesis, diagnosis and treatment. In M. Menza & L. Marsh (Eds.), *Psychiatric issues in Parkinson's disease. A practical guide* (pp. 1–17). London and New York: Taylor & Francis.

Marrie, R.A., Fisk, J.D., Yu, B.N., Leung, S., Elliott, L., Caetano, P., … Patten, S.B. (2013). Mental comorbidity and multiple sclerosis: Validating administrative data to support population-based surveillance. *BMC Neurology*, *13*(1), 1. https://doi.org/10.1186/1471-2377-13-16

Marrie, R.A., Reingold, S., Cohen, J., Stuve, O., Trojano, M., Sorensen, P.S., … Reider, N. (2015). The incidence and prevalence of psychiatric disorders in multiple sclerosis: A systematic review. *Multiple Sclerosis Journal*, *21*(3), 305–317. https://doi.org/10.1177/1352458514564487

Martin, N.H., Lawrence, V., Murray, J., Janssen, A., Higginson, I., Lyall, R., … Goldstein, L.H. (2016). Decision making about gastrostomy and noninvasive ventilation in amyotrophic lateral sclerosis. *Qualitative Health Research*, *26*(10), 1366–1381. https://doi.org/10.1177/1049732315583661

Maxted, C., Simpson, J. & Weatherhead, S. (2014). An exploration of the experience of Huntington's disease in family dyads: An interpretative phenomenological analysis. *Journal of Genetic Counseling*, *23*(3), 339–349. https://doi.org/10.1007/s10897-013-9666-3

McCabe, M. P. & McKern, S. (2002). Quality of life and multiple sclerosis: Comparison between people with multiple sclerosis and people from the general population. *Journal of Clinical Psychology in Medical Settings*, *9*(4), 287–295. https://doi.org/10.1023/A:1020734901150

McDermott, C.J. & Shaw, P.J. (2008, March). Diagnosis and management of motor neurone disease. *BMJ*. https://doi.org/10.1136/bmj.39493.511759.BE

Methley, A., Campbell, S., Cheraghi-Sohi, S. & Chew-Graham, C. (2017). Meeting the mental health needs of people with multiple sclerosis: A qualitative study of patients and professionals. *Disability and Rehabilitation*, *39*(11), 1097–1105. https://doi.org/10.1080/09638288.2016.1180547

Mistry, K.K. & Simpson, J. (2013). Exploring the transitional process from receiving a diagnosis to living with motor neurone disease. *Psychology and Health*, *28*(April 2015), 37–41. https://doi.org/10.1080/08870446.2013.770513

Mohr, D.C., Goodkin, D.E., Bacchetti, P., Boudewyn, A.C., Huang, L., Marrietta, P., … Dee, B. (2000). Psychological stress and the subsequent appearance of new brain MRI lesions in MS. *Neurology*, *55*(1), 55–61. https://doi.org/10.1212/wnl.55.1.55

Mohr, D.C., Likosky, W., Bertagnolli, A., Goodkin, D.E., Van Der Wende, J., Dwyer, P. & Dick, L.P. (2000a). Telephone-administered cognitive–behavioral therapy for the treatment of depressive symptoms in multiple sclerosis. *Journal of Consulting and Clinical Psychology*, *68*(2), 356–361. https://doi.org/10.1037/0022-006x.68.2.356

Mohr, D.C., Boudewyn, A.C., Goodkin, D.E., Bostrom, A. & Epstein, L. (2001). Comparative outcomes for individual cognitive-behavior therapy, supportive-expressive group psychotherapy, and sertraline for the treatment of depression in multiple sclerosis. *Journal of Consulting and Clinical Psychology*, *69*(6), 942–949. https://doi.org/10.1037/0022-006X.69.6.942

Mohr, D.C., Hart, S.L., Julian, L., Catledge, C., Honos-Webb, L., Vella, L. & Tasch, E.T. (2005). Telephone-administered psychotherapy for depression. *Archives Of General Psychiatry*, *62*(9), 1007–1014. https://doi.org/10.1001/archpsyc.62.9.1007

Mohr, David C., Lovera, J., Brown, T., Cohen, B., Neylan, T., Henry, R., … Pelletier, D. (2012). A randomized trial of stress management for the prevention of new brain lesions in MS. *Neurology*, *79*(5), 412–419. https://doi.org/10.1212/WNL.0b013e3182616ff9

Mohr, D.C., Classen, C. & Barrera, M. (2004). The relationship between social support, depression and treatment for depression in people with multiple sclerosis. *Psychological Medicine*, *34*(3), 533–541. https://doi.org/10.1017/S0033291703001235

Mohr, D.C., Hart, S. & Vella, L. (2007). Reduction in disability in a randomized controlled trial of telephone-administered cognitive-behavioral therapy. *Journal of Health Psychology*, *26*(5), 554–563. https://doi.org/10.1037/0278-6133.26.5.554

Moss-Morris, R., McCrone, P., Yardley, L., van Kessel, K., Wills, G. & Dennison, L. (2012). A pilot randomised controlled trial of an Internet-based cognitive behavioural therapy self-management programme (MS Invigor8) for multiple sclerosis fatigue. *Behaviour Research and Therapy*, *50*(6), 415–421. https://doi.org/10.1016/j.brat.2012.03.001

Moss-Morris, R., Dennison, L., Landau, S., Yardley, L., Silber, E. & Chalder, T. (2013). A randomized controlled trial of cognitive behavioral therapy (CBT) for adjusting to multiple sclerosis (the saMS trial): Does CBT work and for whom does it work? *Journal of Consulting and Clinical Psychology*, *81*(2), 251–262. https://doi.org/10.1037/a0029132

Murphy, J.M., Henry, R.G., Langmore, S., Kramer, J.H., Miller, B.L. & Lomen-Hoerth, C. (2007). Continuum of frontal lobe impairment in amyotrophic lateral sclerosis. *Archives of Neurology*, *64*(4), 530–534. https://doi.org/10.1001/archneur.64.4.530

Muscaritoli, M., Kushta, I., Molfino, A., Inghilleri, M., Sabatelli, M. & Rossi Fanelli, F. (2012). Nutritional and metabolic support in patients with amyotrophic lateral sclerosis. *Nutrition*, *28*(10), 959–966. https://doi.org/10.1016/j.nut.2012.01.011

Muslimovic, D., Post, B., Speelman, J.D. & Schmand, B. (2005). Cognitive profile of patients with newly diagnosed Parkinson disease. *Neurology*, *65*(8), 1239–1245. https://doi.org/10.1212/01.wnl.0000180516.69442.95

Nègre-Pagès, L., Grandjean, H., Lapeyre-Mestre, M., Montastruc, J.L., Fourrier, A., Lépine, J.P. & Rascol, O. (2010). Anxious and depressive symptoms in Parkinson's disease: The French cross-sectionnal DoPAMiP study. *Movement Disorders*, *25*(2), 157–166. https://doi.org/10.1002/mds.22760

NHS Wales. (2017). *Neurological Conditions Delivery Plan*.

NICE (2009). Depression in adults with a chronic physical health problem: recognition and management (CG91). https://doi.org/10.1016/j.ijnurstu.2009.08.007

NICE (2011). Generalised anxiety disorder and panic disorder in adults: Management. Retrieved from https://www.nice.org.uk/guidance/cg113/chapter/Key-priorities-for-implementation

NICE (2014). *Multiple sclerosis in adults: Management. NICE clinical guideline CG186*. Retrieved from http://www.nice.org.uk/guidance/cg186/chapter/1-recommendations#modifiable-risk-factors-for-relapse-or-progression-of-ms

NICE (2016). *Motor neurone disease: Assessment and management*. https://doi.org/10.1136/bmj.g4052

NICE (2017). *Parkinson's disease in adults*. Available from: https://www.nice.org.uk/guidance/ng71/resources/parkinsons-disease-in-adults-pdf-1837629189061

Niven, E., Newton, J., Foley, J., Colville, S., Swingler, R., Chandran, S., … Abrahams, S. (2015). Validation of the Edinburgh Cognitive and Behavioural Amyotrophic Lateral Sclerosis Screen (ECAS): A cognitive tool for motor disorders. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *16*(3–4), 172–179. https://doi.org/10.3109/21678421.2015.1030430

Northern Ireland Department of Health. (2019). Review of Neurological Services. Retrieved from https://www.health-ni.gov.uk/rns

Okai, D., Askey-Jones, S., Samuel, M., O'Sullivan, S. S., Chaudhuri, K.R., Martin, A., … David, A.S. (2013). Trial of CBT for impulse control behaviors affecting Parkinson patients and their caregivers.

*Neurology*, *80*(9), 792–799. https://doi.org/10.1212/WNL.0b013e3182840678

Oliver, D., Borasio, G.D. & Walsh, D. (2011). *Palliative care in amyotrophic lateral sclerosis: From diagnosis to bereavement*. https://doi.org/10.1093/acprof:oso/9780199212934.001.0001

Philippopoulos, G.S., Wittkower, E.D. & Cousineau, A. (1958). The etiologic significance of emotional factors in onset and exacerbations of multiple sclerosis; a preliminary report. *Psychosomatic Medicine*, *20*(6), 458–474. https://doi.org/10.1097/00006842-195811000-00003

Phukan, J., Elamin, M., Bede, P., Jordan, N., Gallagher, L., Byrne, S., … Hardiman, O. (2012). The syndrome of cognitive impairment in amyotrophic lateral sclerosis: A population-based study. *Journal of Neurology, Neurosurgery and Psychiatry*, *83*(1), 102–108. https://doi.org/10.1136/jnnp-2011-300188

Phukan, J., Pender, N.P. & Hardiman, O. (2007). Cognitive impairment in amyotrophic lateral sclerosis. *Lancet Neurology*, *6*(November), 994–1003. https://doi.org/10.1016/s1474-4422(07)70265-x

Pickut, B., Vanneste, S., Hirsch, M.A., Van Hecke, W., Kerckhofs, E., Mariën, P., Parizel, P.M., Crosiers, D. & Cras, P. (2015). Mindfulness Training among Individuals with Parkinson's Disease: Neurobehavioral Effects. *Parkinson's disease, 2015,* 816404. https://doi.org/10.1155/2015/816404

Polman, C.H., Reingold, S.C., Banwell, B., Clanet, M., Cohen, J.A., Filippi, M., … Wolinsky, J.S. (2011). Diagnostic criteria for multiple sclerosis: 2010 Revisions to the McDonald criteria. *Annals of Neurology*, *69*(2), 292–302. https://doi.org/10.1002/ana.22366

Pottgen, J., Moss-Morris, R., Wendebourg, J.M., Feddersen, L., Lau, S., Kopke, S., … Gold, S.M. (2018). Randomised controlled trial of a self-guided online fatigue intervention in multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, *89*(9), 970–976. https://doi.org/10.1136/jnnp-2017-317463

Pringsheim, T., Wiltshire, K., Day, L., Dykeman, J., Steeves, T. & Jette, N. (2012). The incidence and prevalence of Huntington's disease: A systematic review and meta-analysis. *Movement Disorders : Official Journal of the Movement Disorder Society*, *27*(9), 1083–1091. https://doi.org/10.1002/mds.25075

Quarrell, O. & Rosser, E. (2014). Uptake for predictive testing for Huntington's disease (HD) in the UK 1993–2012. *Journal of Neurology & Psychiatry*, *85*(Suppl 1), 80–82. http://dx.doi.org/10.1136/jnnp-2014-309032.230

Ringholz, G.M., Appel, S.H., Bradshaw, M., Cooke, N.A., Mosnik, D.M., Schulz, P.E. & Yanagihara, T. (2005). Prevalence and patterns of cognitive impairment in sporadic ALS. *Neurology*, *65*(4), 586–590. https://doi.org/10.1212/01.wnl.0000172911.39167.b6

Rios Romenets, S., Creti, L., Fichten, C., Bailes, S., Libman, E., Pelletier, A. & Postuma, R.B. (2013). Doxepin and cognitive behavioural therapy for insomnia in patients with Parkinson's disease – A randomized study. *Parkinsonism and Related Disorders*, *19*(7), 670–675. https://doi.org/10.1016/j.parkreldis.2013.03.003

Rodgers, S.H., Schutze, R., Gasson, N., Anderson, R.A., Kane, R.T., Starkstein, S., Morgan-Lowes, K., Egan, S.J., Schütze, R., Gasson, N., et al. (2019). Modified mindfulness-based cognitive therapy for depressive symptoms in Parkinson's disease: A pilot trial. *Behavioural and Cognitive Psychotherapy [Internet]. July, 47*, 1–16. https://doi.org/10.1017/s135246581800070x

Roos, R. A. (2014). Clinical neurology. In G Bates, S. Tabrizi & L. Jones (Eds.), *Huntington's disease (4th ed)* (pp. 25–35). Oxford: Oxford University Press.

Roos, R. a C. (2010). Huntington's disease: A clinical review. *Orphanet Journal of Rare Diseases*, *5*(1), 40. https://doi.org/10.1186/1750-1172-5-40

Ryan, K.A., Rapport, L.J., Sherman, T.E., Hanks, R.A., Lisak, R. & Khan, O. (2007). Predictors of subjective well-being among individuals with multiple sclerosis. *Clinical Neuropsychologist*, *21*(2), 239–262. https://doi.org/10.1080/13854040600582460

Scottish Care (2019). *Fragile Foundations: Exploring the Mental Health of the Social Care Workforce and the People they Support.* Available from: https://scottishcare.org/wp-content/uploads/2019/11/Fragile-Foundations-Exploring-the-mental-health-of-the-social-care-workforce-and-the-people-they-support.pdf

Scottish Government (2018). *National Action Plan on Neurological Conditions (Draft for consultation) – 2019–2024.* Available from: https://www.gov.scot/publications/national-action-plan-neurological-conditions-draft-consultation-2019-2024/

Senders, A, Hanes, D., Bourdette, D., Carson, K., Marshall, L.M. & Shinto, L. (2018). Impact of mindfulness-based stress reduction for people with multiple sclerosis at 8 weeks and 12 months: A randomized clinical trial. *Multiple Sclerosis Journal*, 1352458518786650. https://doi.org/10.1177/1352458518786650

Sgoifo, A., Bignamini, A., La Mantia, L., Celani, M. G., Parietti, P., Ceriani, M.A., … Agostoni, E.C. (2017). Integrated imaginative distention therapy to cope with fatigue. DIMMI SI study: The first randomized controlled trial in multiple sclerosis. *Neurology and Therapy*, *6*(2), 213–223. https://doi.org/10.1007/s40120-017-0081-9

Scottish Huntington's Association (2019a). *Guiding Principles of the National Care Framework.* Retrieved from http://care.hdscotland.org/

Scottish Huntington's Association (2019b). National Care Framework for Huntington's Disease. Retrieved from http://care.hdscotland.org/

Shulman, L.M., Taback, R.L., Rabinstein, A.A. & Weiner, W.J. (2002). Non-recognition of depression and other non-motor symptoms in Parkinson's disease. *Parkinsonism and Related Disorders*, *8*(3), 193–197. https://doi.org/10.1016/S1353-8020(01)00015-3

Siddiqui, M.K., Khurana, I.S., Budhia, S., Hettle, R., Harty, G. & Wong, S.L. (2018). Systematic literature

review and network meta-analysis of cladribine tablets versus alternative disease-modifying treatments for relapsing–remitting multiple sclerosis. *Current Medical Research and Opinion*, *34*(8), 1361–1371. https://doi.org/10.1080/03007995.2017.1407303

Siegert, R.J. & Abernethy, D.A. (2005). Depression in multiple sclerosis: A review. *Journal of Neurology, Neurosurgery and Psychiatry*, *76*(4), 469–475. https://doi.org/10.1136/jnnp.2004.054635

SIGN (2010). *Diagnosis and pharmacological management of Parkinson's disease* (Vol. January). https://doi.org/10.1136/bmj.b5614

Simpson, J., Dale, M., Theed, R., Gunn, S., Zarotti, N. & Eccles, F. (2019). Validity of irritability in Huntington's disease: A scoping review. *Cortex*. https://doi.org/10.1016/j.cortex.2019.06.012

Simpson, J., Lekwuwa, G. & Crawford, T. (2013). Illness beliefs and psychological outcome in people with Parkinson's disease – Applied Social Sciences Index and Abstracts (ASSIA) – ProQuest. *Chronic Illness*, *9*(2), 165–176. https://doi.org/10.1177/1742395313478219

Simpson, J., McMillan, H., Leroi, I. & Murray, C.D. (2015). Experiences of apathy in people with Parkinson's disease: A qualitative exploration. *Disability and Rehabilitation*, *37*(7), 611–619. https://doi.org/10.3109/09638288.2014.939771

Simpson, J., McMillan, H. & Reeve, D. (2013). Reformulating psychological difficulties in people with Parkinson's disease: The potential of a social relational approach to disablism. *Parkinson's Disease, 2013*. https://doi.org/10.1155/2013/608562

Simpson, J. & Thomas, C. (2015). Clinical psychology and disability studies: Bridging the disciplinary divide on mental health and disability. *Disability and Rehabilitation*, *37*(14), 1299–1304. https://doi.org/10.3109/09638288.2014.961656

Simpson, R, Mair, F.S. & Mercer, S.W. (2017). Mindfulness-based stress reduction for people with multiple sclerosis – a feasibility randomised controlled trial. *BMC Neurology*, *17*(1), 94. https://doi.org/10.1186/s12883-017-0880

Sinclair, V.G. & Scroggie, J. (2005). Effects of a cognitive-behavioral program for women with multiple sclerosis. *Journal of Neuroscience Nursing*, *37*(5), 249–257,276. https://doi.org/10.1097/01376517-200510000-00004

Smith, S., D'Cruz, G., Gray, R., Flaherty, H., Ivanecka, A. & Deane, K.H.O. (2015). A concept map of what helps people with HD live with their condition. *Journal of Huntington's Disease*, *4*(3), 260–270. https://doi.org/10.3233/JHD-150161

Sobel, S. (2005). Thursdays with Marion: The therapist's tale. *Journal of Genetic Counseling*, *14*(5), 341–347. https://doi.org/10.1007/s10897-005-0798-x

Soh, S.E., Morris, M.E. & McGinley, J.L. (2011). Determinants of health-related quality of life in Parkinson's disease: A systematic review. *Parkinsonism and Related Disorders*, *17*(1), 1–9. https://doi.org/10.1016/j.parkreldis.2010.08.012

Son HG, Choi EO.(2018). The effects of mindfulness meditation-based complex exercise program on motor and nonmotor symptoms and quality of life in patients with Parkinson's disease. *Asian Nurs Res (Korean Soc Nurs Sci)*. 2018;12:145–153. https://doi.org/10.1016/j.anr.2018.06.001

Stanton, A.L. & Revenson, T.A. (2012). Adjustment to chronic disease: Progress and promise in research. In *The Oxford Handbook of Health Psychology* (pp. 241–268). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780195342819.013.0011

Stavroulakis, T., Baird, W.O., Baxter, S.K., Walsh, T., Shaw, P.J. & McDermott, C.J. (2014). Factors influencing decision-making in relation to timing of gastrostomy insertion in patients with motor neurone disease. *BMJ Supportive and Palliative Care*, *4*(1), 57–63. https://doi.org/10.1136/bmjspcare-2013-000497

Stavroulakis, T., Baird, W.O., Baxter, S.K., Walsh, T., Shaw, P.J. & McDermott, C.J. (2016). The impact of gastrostomy in motor neurone disease: Challenges and benefits from a patient and carer perspective. *BMJ Supportive and Palliative Care*, *6*(1), 52–59. https://doi.org/10.1136/bmjspcare-2013-000609

Sullivan, C.L., Wilken, J.A. & Rabin, B.M. (2004). *Psychosocial Adjustment to Multiple Sclerosis,* 98–105.

Tesar, N., Baumhackl, U., Kopp, M. & Gunther, V. (2003). Effects of psychological group therapy in patients with multiple sclerosis. *Acta Neurologica Scandinavica, 107*(6), 394–399. https://doi.org/10.1034/j.1600-0404.2003.00077.x

The Neurological Alliance (2017). *A report by the Neurological Alliance Parity of Esteem for People affected by Neurological Conditions*. Retrieved from https://www.neural.org.uk/assets/pdfs/2017-07-parity-of-esteem.pdf

The Neurological Alliance. (2018). *The long term plan for the National Health Service (NHS): Getting it right for neurology patients*. Retrieved from https://www.neural.org.uk/assets/pdfs/2018-08-long-term-plan-for-nhs.pdf

The Neurological Alliance. (2019a). *Consensus statement on mental , emotional and cognitive health provision. Retrieved from www.neural.org.uk/wp-content/uploads/*2019/06/Mental-Health-Consensus-Statement.pdf

The Neurological Alliance (2019b). *Neuro Patience, Still waiting for improvements in treatment care*. Retrieved from https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-patience-2019-1.pdf

Thomas, S., Thomas, P.W., Kersten, P., Jones, R., Green, C., Nock, A., … Hillier, C. (2013). A pragmatic parallel arm multi-centre randomised controlled trial to assess the effectiveness and cost-effectiveness of a group-based fatigue management programme (FACETS) for people with multiple sclerosis. *Journal of Neurology, Neurosurgery, and Psychiatry*, *84*(10), 1092–1099. https://doi.org/10.1136/jnnp-2012-303816

Tiihonen, S., Lankinen, A. & Viemerö, V. (2012). An evaluation of a cognitive-behavioral patient education program for persons with Parkinson's disease in Finland. *Nordic Psychology*, *60*(4), 316–331. https://doi.org/10.1027/1901-2276.60.4.316

Todd, D., Simpson, J. & Murray, C. (2010). An interpretative phenomenological analysis of delusions in people with Parkinson's disease. *Disability and Rehabilitation*, *32*(15), 1291–1299. https://doi.org/10.3109/09638280903514705

Trapp, B.D. & Nave, K.-A. (2008). Multiple sclerosis: An immune or neurodegenerative disorder? *Annual Review of Neuroscience*, *31*(1), 247–269. https://doi.org/10.1146/annurev.neuro.30.051606.094313

Troeung L., Egan, S.J., Gasson, N.A (2014). Waitlist-controlled trial of group cognitive behavioural therapy for depression and anxiety in Parkinson's disease. *BMC Psychiatry. 14*(19). https://doi.org/10.1186/1471-244X-14-19

Truong, D.D., Bhidayasiri, R. & Wolters, E. (2008). Management of non-motor symptoms in advanced Parkinson disease. *Journal of the Neurological Sciences*, *266*(1–2), 216–228. https://doi.org/10.1016/j.jns.2007.08.015

Underwood, M., Bonas, S. & Dale, M. (2017). Huntington's disease: Prevalence and psychological indicators of pain. *Movement Disorders Clinical Practice*, *4*(2), 198–204. https://doi.org/10.1002/mdc3.12376

van den Akker, Lizanne E., Beckerman, H., Collette, E. H., Twisk, J.W.R., Bleijenberg, G., Dekker, J., … de Groot, V. (2017). Cognitive behavioral therapy positively affects fatigue in patients with multiple sclerosis: Results of a randomized controlled trial. *Multiple Sclerosis*, *23*(11), 1542–1553. https://doi.org/10.1177/1352458517709361

van Kessel, K, Moss-Morris, R., Willoughby, E., Chalder, T., Johnson, M.H. & Robinson, E. (2008). A randomized controlled trial of cognitive behavior therapy for multiple sclerosis fatigue. *Psychosomatic Medicine*, *70*(2), 205–213. 10.1097/PSY.0b013e3181643065

van Kessel, Kirsten, Wouldes, T. & Moss-Morris, R. (2016). A New Zealand pilot randomized controlled trial of a web-based interactive self-management programme (MSInvigor8) with and without email support for the treatment of multiple sclerosis fatigue. *Clinical Rehabilitation*, *30*(5), 454–462. https://doi.org/10.1177/0269215515584800

van der Meer, L. B., van Duijn, E., Wolterbeek, R. & Tibben, A. (2012). Adverse childhood experiences of persons at risk for Huntington's disease or BRCA1/2 hereditary breast/ovarian cancer. *Clinical Genetics*, *81*(1), 18–23. https://doi.org/10.1111/j.1399-0004.2011.01778.x

van Duijn, E., Craufurd, D., Hubers, A.A.M., Giltay, E.J., Bonelli, R., Rickards, H., … Landwehrmeyer, G.B. (2014). Neuropsychiatric symptoms in a European Huntington's disease cohort (REGISTRY). *Journal of Neurology, Neurosurgery and Psychiatry*, *85*(12), 1411–1418. https://doi.org/10.1136/jnnp-2013-307343

Wahlin, T.-B.R. (2007). To know or not to know: A review of behaviour and suicidal ideation in preclinical Huntington's disease. *Patient Education and Counseling*, *65*(3), 279–287. https://doi.org/10.1016/j.pec.2006.08.009

Walker, F.O. (2007). Huntington's disease. *Lancet*, *27*(2), 143–150. https://doi.org/10.1055/s-2007-971176

Walshe, M. & Miller, N. (2011). Living with acquired dysarthria: The speaker's perspective. *Disability and Rehabilitation*, *33*(3), 195–203. https://doi.org/10.3109/09638288.2010.511685

Walshe, M., Peach, R.K. & Miller, N. (2009). Dysarthria impact Profile development of a scale to measure psychosocial effects. *International Journal of Language and Communication Disorders*, *44*(5), 693–715. https://doi.org/10.1080/13682820802317536

Weeks, K.R., Gould, R.L., Mcdermott, C., Lynch, J., Goldstein, L.H., Graham, C.D., … Lawrence, V. (2019). Needs and preferences for psychological interventions of people with motor neurone disease. *Amyotrophic Lateral Sclerosis & Frontotemporal Degeneration*, *20*(7–8), 521–531. https://doi.org/10.1080/21678421.2019.1621344

Weiner, H.L. (2008). A shift from adaptive to innate immunity: A potential mechanism of disease progression in multiple sclerosis. *Journal of Neurology*, *255*(SUPPL. 1), 3–11. https://doi.org/10.1007/s00415-008-1002-8

Weintraub, D. & Burn, D.J. (2011). Parkinson's disease: The quintessential neuropsychiatric disorder. *Movement Disorders*, *26*(6), 1022–1031. https://doi.org/10.1002/mds.23664

Wendebourg, M.J., Feddersen, L.K., Lau, S., Kopke, S., Moss-Morris, R., Heesen, C. & Pottgen, J. (2016). Development and feasibility of an evidence-based patient education program for managing fatigue in multiple sclerosis: The 'Fatigue management in MS' program (FatiMa). *International Journal of MS Care*, *18*(3), 129–137. https://doi.org/10.7224/1537-2073.2014

Williams, J. & Erwin, C. (2010). In their own words: Reports of stigma and genetic discrimination by people at risk for Huntington disease in the International RESPOND-HD study. *American Journal of Medical Genetics,* 1–18. https://doi.org/10.1002/ajmg.b.31080.

Willis, A.W., Schootman, M., Kung, N. & Racette, B. A. (2013). Epidemiology and neuropsychiatric manifestations of Young Onset Parkinson's Disease in the United States. *Parkinsonism and Related Disorders*, *19*(2), 202–206. https://doi.org/10.1016/j.parkreldis.2012.09.014

Wood, B., Van Der Mei, I.A.F., Ponsonby, A.L., Pittas, F., Quinn, S., Dwyer, T., … Taylor, B.V. (2013). Prevalence and concurrence of anxiety, depression and fatigue over time in multiple sclerosis. *Multiple Sclerosis Journal*, *19*(2), 217–224. https://doi.org/10.1177/1352458512450351

Worms, P.M. (2001). The epidemiology of motor neurone diseases: a review of recent studies. *Journal of the Neurological Sciences*, *191*(1–2), 3–9. https://doi.org/10.1016/S0022-510X(01)00630-X

Wuthrich, V.M., Rapee, R.M. (2019). Telephone-delivered cognitive behavioural therapy for treating symptoms of anxiety and depression in Parkinson's disease: A pilot trial.*Journal of Clinical Gerontology and Geriatrics. July*

*1,* 42:444–453. https://doi.org/10.1080/07317115.2019.1580811

You, S.C., Geschwind, M.D., Sha, S.J., Apple, A., Satris, G., Wood, K.A., … Possin, K.L. (2014). Executive functions in premanifest Huntington's disease. *Movement Disorders*, *29*(3), 405–409. https://doi.org/10.1002/mds.25762

Zarei, S., Carr, K., Reiley, L., Diaz, K., Guerra, O., Altamirano, P., … Chinea, A. (2015). A comprehensive review of amyotrophic lateral sclerosis. *Surgical Neurology International*, *6*(1), 171. https://doi.org/10.4103/2152-7806.169561

Zarotti, N., Coates, E., McGeachan, A., Williams, I., Beever, D., Hackney, G., … Young, T. (2019). Health care professionals' views on psychological factors affecting nutritional behaviour in people with motor neurone disease: A thematic analysis. *British Journal of Health Psychology*, *24*(4), 953–969. https://doi.org/10.1111/bjhp.12388

Zarotti, N., Dale, M., Eccles, F. & Simpson, J. (2020). Psychological interventions for people with Huntington's disease: A call to arms. *Journal of Huntington's Disease, 9*(3), 231–243. https://doi.org/10.3233/JHD-200418

Zarotti, N., Eccles, F.J.R., Foley, J.A., Paget, A., Gunn, S., Leroi, I. & Simpson, J. (2020). Psychological interventions for people with Parkinson's disease in the early 2020s: Where do we stand? *Psychology and Psychotherapy: Theory, Research, and Practice.* https://doi.org/10.1111/papt.12321

Zarotti, N., Fletcher, I. & Simpson, J. (2018). New perspectives on emotional processing in people with symptomatic Huntington's disease: Impaired emotion regulation and recognition of emotional body language. *Archives of Clinical Neuropsychology*, *acy085*, 1–15. https://doi.org/10.1093/arclin/acy085

Zarotti, N., Mayberry, E., Ovaska-stafford, N., Eccles, F. & Simpson, J. (2020). Psychological interventions for people with motor neurone disease: A scoping review. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, *0*(0), 1–11. https://doi.org/10.1080/21678421.2020.1788094

Zarotti, N., Simpson, J. & Fletcher, I. (2019). 'I have a feeling I can't speak to anybody': A thematic analysis of communication perspectives in people with Huntington's disease. *Chronic Illness, 15*(1), 61–73. https://doi.org/10.1177/1742395317733793

Zarotti, N., Simpson, J., Fletcher, I., Squitieri, F. & Migliore, S. (2018). Exploring emotion regulation and emotion recognition in people with presymptomatic Huntington's disease: The role of emotional awareness. *Neuropsychologia*, *112*, 1–9. https://doi.org/10.1136/jnnp-2018-ehdn.151

Zhang, Z.X. & Roman, G.C. (1993). Worldwide occurrence of Parkinson's disease: An updated review. *Neuroepidemiology*, *12*(4), 195–208. https://doi.org/10.1159/000110318

APPENDIX A

# Glossary of therapies

# Glossary of therapies

## ACCEPTANCE AND COMMITMENT THERAPY (ACT)

ACT aims to improve individuals' acceptance of distressing thoughts, beliefs, sensations and emotions, contending that this will generate behavioural change and consequently improve quality of life. There is emphasis on moving towards key goals and acting upon values which are most important to the person, designing behavioural changes which direct one towards living these values.

### KEY REFERENCES

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2012). *Acceptance and commitment therapy: The process and practice of mindful change (2nd ed.).* New York: Guilford Press.

## COGNITIVE BEHAVIOURAL THERAPY (CBT)

CBT holds that emotional distress and behavioural difficulties arise from 'maladaptive' or unhelpful cognitions, which comprise general beliefs about the world, the self and the future. The therapy is predicated on the assumption that changing these cognitions through therapeutic interventions will reduce distress and problematic behaviours.

### KEY REFERENCES

Beck, A. T. (1970). Cognitive therapy: Nature and relation to behavior therapy. *Behavior Therapy, 1,* 184-200.

Beck, J.S. (2011). *Cognitive Behavior Therapy, Second Edition: Basics and Beyond.* The Guilford Press: New York.

Hofmann, S. G., Asnaani, A., Vonk, I. J. J., Sawyer, A. T. & Fang, A. (2012). The efficacy of cognitive behavioural therapy: A review of meta-analyses. *Cognitive Therapy and Research, 36*(5), 427-440. https://doi.org/10.1007/s10608-012-9476-1

## DIALECTICAL BEHAVIOUR THERAPY (DBT)

DBT was developed from CBT; it retains the focus on changing unhelpful cognitions and behaviours to improve wellbeing, but places additional importance upon self-acceptance, validation of experiences, and emotional regulation/coping. While usually associated with individuals given the diagnosis of borderline personality disorder, DBT is increasingly being used with other client groups. The emphasis on acceptance and emotional management may be particularly helpful for individuals adjusting to lifelong, or life-limiting, neurological diagnoses.

### KEY REFERENCES

Dimeff, L. A., & Koerner, K. (2007). Dialectical behavior therapy in clinical practice: Applications across disorders and settings. New York: Guilford Press.

Linehan, M. M. (2014). DBT skills training manual (2nd ed.). New York: Guilford Press.

## DIGNITY THERAPY

Dignity therapy is a time-limited approach based on an empirically-validated model of dignity in people at the end of life. Participants are invited to discuss the issues that matter the most to them or that they most want to be remembered about their life. Sessions are transcribed and returned to the individuals, to be bequeathed to someone important to them.

### KEY REFERENCES

Aoun, S. M., Chochinov, H. M., & Kristjanson, L. J. (2015). Dignity therapy for people with motor neuron disease and their family caregivers: a feasibility study. Journal of Pallative Medicine, 18(1), 31–37. https://doi.org/10.1089/jpm.2014.0213

Chochinov, H. M. (2002). Dignity-conserving care – a new model for palliative care: Helping the patient feel valued. Journal of the American Medical Association, 287(17), 2253-2260. https://doi.org/10.1001/jama.287.17.2253

Martinez, M., Arantzamendi, M., Belar, A., Carrasco J. M., Carvajal, A., Rullán, M., & Centeno, C. (2017). 'Dignity therapy', a promising intervention in palliative care: A comprehensice systematic literature review. Palliative Medicine, 31(6), 492-509. https://doi.org/10.1177/0269216316665562

## EMOTION-FOCUSED THERAPY

Emotion-focused therapy centres around the development of emotional intelligence and secure relationships, examining the goals and values of key relationships for the individual and improving emotional skills. The therapy has its roots in attachment theory and it is argued that pain and disruption within close relationships are an expression of a need for attachment which, when fulfilled, will result in improved well-being and closer relationships.

### KEY REFERENCES

Greenberg, L. S. (2004). Emotion-focused therapy. Clinical Psychology and Psychotherapy, 11, 3-16. https://doi.org/10.1002/cpp.388

## EYE MOVEMENT DESENSITISATION AND REPROCESSING (EMDR)

EMDR focuses on reprocessing traumatic memories, including images, emotional and physical responses, and changes in self-representation which are associated with the memory. The aim is to help process the trauma neurologically, helping individuals develop more positive self-representation, improve well-being and move forward with their lives.

### KEY REFERENCES

Shapiro, F. (2017). Eye movement desensitization and reprocessing (EMDR) therapy: Basic principles, protocols, and procedures (3rd ed.). New York: Guilford Press.

## MINDFULNESS-BASED APPROACHES

Mindfulness-based approaches focus on bringing the attention to the present moment and accepting feelings, sensations and emotions non-judgementally, including the experience of illness. Such approaches developed for neurological conditions may emphasise acceptance of discomfort and physical changes, focusing on relaxation and appreciation of the abilities and resources which remain. Approaches may include elements of cognitive therapy (MBCT) or may focus on stress reduction (MBSR).

### KEY REFERENCES

Crane, R. (2017). Mindfulness-based cognitive therapy. London: Routledge.

Kabat-Zinn, J. (2006). Mindfulness-Based Interventions in Context: Past, Present, and Future. Clinical Psychology: Science and Practice, 10(2), 144–156. https://doi.org/10.1093/clipsy.bpg016

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2013). Mindfulness-based cognitive therapy for depression (2nd ed.). New York: New York: Guilford Press.

## PSYCHODRAMA

Psychodrama is a form of art therapy based on discussions of interactions and the dramatisation and role-playing of situations of daily life from an individual's past. As a therapeutic technique, it explores individuals' difficulties by employing guided dramatic action based on spontaneity and creativity, with the aim of stimulating the expression of suppressed emotions.

### KEY REFERENCES

Moreno, J. T. (1946). Psychodrama and Group Psychotherapy. Sociometry, 9(2/3), 249–253.

Dehnavi, S., Mohammadi, A. Z., & HassaniRaad, M. (2019). Effectiveness of unity-oriented psychodrama on sense of coherence of MS patients. Iranian Journal of Psychiatry and Behavioral Sciences, 13(1). https://doi.org/10.5812/ijpbs.5869

## PSYCHOEDUCATION

Psychoeducation focuses on developing individuals' understanding about their illness and how they live with the condition by providing accurate information and by practising and rehearsing different scenarios to help improve control. The aim is to empower the individual to manage their condition and their own reactions to it more successfully and consequently improve their well-being. Programmes may include elements of CBT (e.g., cognitive restructuring), behavioural activation, development of stress coping strategies, social skills training, role play, and relaxation skills development. Content is tailored to the specific condition (examples from studies on HD, MS and PD are in the references below).

### KEY REFERENCES

A'Campo, L. E. I., Spliethoff-Kamminga, N. G. A., & Roos, R. A. C. (2012). The Patient Education Program for Huntington's Disease (PEP-HD). Journal of Huntington's Disease, 1(1), 47–56. https://doi.org/10.3233/JHD-2012-120002

Macht, M, Gerlich, C., Ellgring, H., Schradi, M., Rusinol, A. B., Crespo, M., … Kanarik, E. (2007). Patient education in Parkinson's disease: Formative evaluation of a standardized programme in seven European countries. Patient Education and Counselling, 65(2), 245–252. https://doi.org/10.1016/j.pec.2006.08.005

McGuire, K. B., Stojanovic-Radic, J., Strober, L., Chiaravalloti, N. D., & DeLuca, J. (2015). Development and effectiveness of a psychoeducational wellness program for people with multiple sclerosis: description and outcomes. Internation Journal of MS Care, 17(1), 1–8. https://doi.org/10.7224/1537-2073.2013-045

Walsh, J. (2010). Psychoeducation in mental health. Oxford: Oxford Unversity Press.

## RELAXATION TRAINING (INCL. PROGRESSIVE MUSCLE RELAXATION)

Relaxation-based interventions focus on relieving muscle tension, on the hypothesis that muscular tension is a physiological response to anxiety, and that therefore relaxing the muscles will reduce anxiety. Techniques may involve progressive attention to muscle groups, tensing and releasing in turn while focusing on the sensation of release following tension, and this may be supported by relaxing music or guided narratives to assist the exercises.

### KEY REFERENCES

McCallie, M. S., Blum, C. M., & Hood, C. J. (2006). Progressive muscle relaxation. Journal of Human Behavior in the Social Environment, 13(6), 51-66.

## REMOTIVATION THERAPY

Remotivation therapy is a five-step, structured technique which focuses on increasing quality of life by improving self-awareness, and restoring/maintaining social and mental functioning. It focuses on motivating and engaging individuals to seek fulfilment, focusing on abilities rather than their absence, and was originally intended for use with people who had become non-verbal and withdrawn. It has since been shown to be effective in other neurological conditions, and was trialled in HD in Sullivan et al.'s (2001) study.

### KEY REFERENCES

Dyer, J. A., & Stott, M. L. (Eds.). Handbook of remotivation therapy. New York: Haworth Clinical Practice Press.

Sullivan, F. R., Bird, E. D., Alpay, M., & Cha, J. H. (2001). Remotivation therapy and Huntington's disease. Journal of Neuroscience Nursing, 33(3), 136–142. https://doi.org/10.1097/01376517-200106000-00005

APPENDIX B

# Acronyms and abbreviations

# Acronyms and abbreviations



## A

| | |
|---|---|
| **ACT** | Acceptance and commitment therapy |
| **ALS** | Amyotrophic lateral sclerosis |
| **APPG** | All-Party Parliamentary Group |

## C

| | |
|---|---|
| **CBT** | Cognitive behavioural therapy |
| **CBTi** | Cognitive behavioural therapy for insomnia |
| **CIS** | Clinically Isolated Syndrome |
| **CNS** | Central nervous system |

## D

| | |
|---|---|
| **DBT** | Dialectical behaviour therapy |

## E

| | |
|---|---|
| **EMDR** | Eye movement desensitisation and reprocessing |

## H

| | |
|---|---|
| **HD** | Huntington's disease |
| **HDA** | Huntington's Disease Association |
| **HTT** | The Huntingtin protein |

## I

| | |
|---|---|
| **IAPT** | Improving Access to Psychological Therapies |

## M

| | |
|---|---|
| **MBCT** | Mindfulness-based cognitive therapy |
| **MBSR** | Mindfulness-based stress reduction |
| **MND** | Motor neurone disease |
| **MS** | Multiple sclerosis |

## N

| | |
|---|---|
| **NICE** | The National Institute for Health and Care Excellence |

## O

| | |
|---|---|
| **OCD** | Obsessive-compulsive disorder |

## P

| | |
|---|---|
| **PD** | Parkinson's disease |
| **PDD** | Parkinson's disease dementia |
| **PD-MCI** | Mild cognitive impairment in Parkinson's disease |
| **PPMS** | Primary progressive MS |
| **PRMS** | Progressive-relapsing MS |
| **PTSD** | Post-traumatic stress disorder |
| **pwHD** | Person or people with HD |
| **pwMND** | Person or people with MND |
| **pwMS** | Person or people with MS |
| **pwPD** | Person or people with PD |

## R

| | |
|---|---|
| **RCT** | Randomised controlled trial |
| **RIS** | Radiologically Isolated Syndrome |
| **RRMS** | Relapsing-remitting MS |

## S

| | |
|---|---|
| **SIGN** | Scottish Intercollegiate Guidelines Network |
| **SPMS** | Secondary progressive MS |
| **SSRIs** | Selective serotonin reuptake inhibitors |

the british
psychological society
promoting excellence in psychology

St Andrews House
48 Princess Road East
Leicester LE1 7DR, UK

0116 254 9568 0116 227 1314 info@bps.org.uk

www.bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642

REP143/01.2021