Reference Guide for Allied Health Professionals working with people with Rapidly Progressing Neurological Disease

Developed by the Herts, Essex and North East London Rapidly Progressing Neurological Disease Palliative Care Network

A Professionals Guide
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Feel free to use and distribute this guide but please acknowledge the authors and origin of the document.

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Reference Guide for Allied Health Professionals working with people with Rapidly Progressing Neurological Disease

Developed by the Herts, Essex and North East London Rapidly Progressing Neurological Disease Palliative Care Network

Introduction

This Reference Guide has been developed by a group of Allied Health Professionals (AHPs – see acknowledgements) who work within the NHS, social care and the voluntary sector, particularly hospices, in response to their experience of the variable standard of care for patients with rapidly progressing neurological diseases (RPND). Patients with this group of diseases, which includes Corticobasal syndrome (CBS), Huntington’s Disease (HD), Motor Neurone disease (MND), Multiple System Atrophy (MSA) and Progressive Supranuclear Palsy (PSP) are frequently seen by generalist AHPs who have minimal or no experience in managing the complexities that these patients face. This reference guide is designed to give advice on how best to use the skills that are already present and how to apply these effectively with this patient group.

Background

Despite the publication of the National Service Framework (NSF) for Long Term Conditions by the Department of Health in March 2005, there is clear evidence to show that people with RPND are currently underserved by the National Health Service (NHS) resulting in “a 32% increase in emergency admissions and the increased rate of readmissions to hospital within 28 days from 11.2% to 14% since the introduction of the NSF” (House of Commons Report 2010-2012).

The report goes on to say “People with neurological conditions need a wide range of services that can cross boundaries between health and social care, employment and benefit services, transport, housing and education. Despite these complex needs, coordination of care for individuals is poor, and there is a lack of integration between health and social services”.

This gap in provision of care presented a real opportunity for the working group involved in producing this document to take a leadership role in improving the general understanding of RPND, providing an accessible reference guide for AHPs, general practitioners, healthcare colleagues specialising in neurology and palliative care and Clinical Commissioning Groups. The ambition is to achieve the highest standard of holistic care from diagnosis to end of life for each individual experiencing
these neurological conditions, their carers and family, by providing examples of best clinical, social and therapeutic practice.

Kumar (2007) wrote “We are all born to die. But most people die in misery. A huge percentage of this misery is unwarranted, as it can be settled with good quality palliative care”.

The imperative to develop high quality, thoughtful and holistic palliative and end of life care was set out in the Demos report *Dying for Change*, asserting “to allow people the deaths they want, end of life care must be radically transformed” (Garber and Leadbeater 2010).

This guidance should help all those involved in patients’ care be part of that *radical transformation*, recognising that the physical, emotional and spiritual wellbeing of each individual really matters.

“You matter because you are you, you matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die”. *Dame Cicely Saunders.*

This reference guide starts with key recommendations that all AHPs should be aware of and working to achieve throughout their contact with each patient with a RPND. Many of the symptoms experienced by this patient population are similar, therefore they have been grouped together. A “quick reference” guide has been provided as the next part of the reference guide, summarising the key difficulties and the questions all AHPs should ask of their patients. More depth of information regarding specific symptoms and the role each AHP should play in the management of this then makes up the full guidelines. Following that section, the symptoms that are disease specific are then highlighted.
Key Recommendations

- **Ask the Question**
  - Do not be afraid to ask questions, even if it is not your speciality.

- **Be confident in your own abilities**
  - Use your existing assessment skills.
  - Be aware of where you may need specialist help.

- **Be Creative**
  - Look for alternative solutions.
  - Think out of the box.

- **Plan ahead**
  - These patients can decline rapidly.
  - Encourage the patient and family to plan ahead, both formally through the use of advanced care planning documents and informally through discussion (see appendix 1).
  - Work at their pace but try to be aware of changes looming to avoid crises.
  - Be one step ahead.
  - Timely response and referral on is vital.

- **Good communication skills**
  - Good communication skills are key to success in this area, because of the complex nature of the conditions and the problems that arise.
  - If you cannot have some of the difficult conversations needed be aware of who can.

- **Holistic assessment**
  - These conditions affect a lot of aspects of the patient’s daily life.
  - Check the patient’s priorities and work with them where possible.

- **Goal setting**
  - Careful negotiation with the patient will be required.
  - Set small, achievable goals where possible.
  - Accept the patient may have unachievable goals but that may give them hope.
  - Maintenance is a more realistic goal than improvement in most instances.
  - Quality of life as it means to the patient is what is important.
• **Early and ongoing involvement**
  - Early referral to AHPs will be important.
  - It is important that the right professional is involved at the right time.
  - Episodic care is not recommended for these patients as their needs can change frequently. Ongoing assessment and review is needed.

• **Palliative Care**
  - All patients with RPND are palliative from diagnosis.
  - Early referral should be made to palliative care services to open up a number of opportunities for support for the patient, their carers and professionals.
  - Different palliative care teams will offer different services, familiarise yourself with your own local services.

• **Carers**
  - As communication difficulties and fatigue are common in this group of patients it is important to involve carers when gathering information.
  - The demands on carers are high and support is very important to prevent breakdown.

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**STAFF WELLBEING**

This group of patients can be particularly emotionally challenging for an AHP to be involved with. There is likely to be regular contact with these patients over some time and the progressive nature of the conditions can lead to a feeling of helplessness for professionals. The death of a patient they have been involved with for some time can also be very challenging. It is vitally important to be self aware and seek support from colleagues or other professionals when required. Being part of a multi professional team can help with this. Many hospices have formal supervision structures in place to support their staff in dealing with these circumstances and it is recommended that AHPs seek this support in their organisation.
QUICK REFERENCE GUIDE

A genuine holistic assessment, is the key to successful management with these patients. This reference guide does not cover symptoms commonly experienced by patients with a neurological disease but deals with the more complex problems that are specific to patients with RPND.

N. B. For more detail please see Page 13 onwards.

PSYCHOLOGICAL NEEDS

COGNITION

- Early cognitive impairment.
- Timely assessment.
- Baseline assessment.

**Ask the question** – Have you noticed any changes in your memory or other cognitive function?

DEPRESSION

- Not just inevitable.
- Needs to be treated.

**Ask the question** – Have you seen any changes to your mood?

PHYSICAL NEEDS

NUTRITION AND HYDRATION

- Higher energy requirements.
- Swallow changes.
- Social changes with loss of eating.

**Ask the Question** – Have you been losing weight/have you noticed changes in how your clothes fit? Are you finding it difficult to eat or drink?

CONSTIPATION

- Changes in bowel motility.
- Reduced overall mobility.
- Lack of sufficient hydration.
- Affects a patient’s tone and functional abilities.

**Ask the Question** – Are you opening your bowels regularly and easily?
SALIVATION
- Excess saliva or dry mouth.

Ask the Question - Are you troubled by saliva or excessive dribbling?

COMMUNICATION
- Changes may happen quickly.
- Will progress and limit ability of patient to communicate needs.
- Consider receptive and expressive language needs.

Ask the question – Are you having difficulty making yourself understood or understanding others?

FATIGUE
- Impacts on every other function.
- Cognitive changes might limit ability to manage it.

Ask the Question – Do you feel a tiredness that isn’t relieved by sleep and is affecting your every day abilities?

FUNCTION
- Rapid decline in their physical functioning.
- Be aware of local and national services that may be able to provide or fund specialist equipment.

Ask the Question – How are you managing with your day to day tasks?

DRIVING
- Multiple difficulties will impact on safety to drive.

Ask the question – Would you be able to stop in an emergency? Is your ability to control the vehicle at all times as good as it was?

RESPIRATORY CHANGES
- Some patients experience respiratory changes associated with muscle weakness.
- This can lead to a weakened cough.

Ask the Question – Have you noticed any changes to your breathing? Are you coughing more than usual? Do you have poor sleep?
PAIN
- May have physical pain or total pain.
- Refer to either a specialist pain team or a palliative care team if not under control.

Ask the Question – Do you experience any pain, feel it is not effectively controlled or that you are not coping with it?

PRESSURE AREAS
- Patients at risk of pressure sores.
- May be in unusual areas.
- Due to sensation changes, patient may not be aware of pain associated with early stage of sore.

Ask the Question – Do you have any red, sore or broken areas of skin?

INTIMACY
- May be affected by changes in libido, body image, by the physical limitations
- Some patients experience some disinhibition.
- Be aware of cultural restrictions when discussing intimacy and sexuality.

Ask the Question – Is your condition affecting your intimate relationships? Have things changed in the physical relationship between you and your partner?

EMOTIONAL NEEDS
- Patients may experience loss of hope, fear, lack of control, anxiety and frustration.

Ask the question – Are you feeling anxious or out of control?

SPIRITUAL NEEDS
- Spirituality may be a significant issue for patients with RPND as they are facing rapidly progressive disease and imminent death. An awareness of the impact of this is important as it may over ride all other symptoms.

Ask the Question – What helps you cope with all that is going on for you right now?
FINANCIAL NEEDS

- Be aware of local or national organisations that may be able to give advice.
- Patients may still be working at an early stage of their disease, be aware of the support with “Access to work”.

**Ask the Question** – Do you have any financial concerns?

SOCIAL NEEDS

HOUSING

- Physical condition may necessitate changes in housing, but time is likely to be too short for some solutions.

**Ask the Question** – Is your current housing suitable for your needs?

SOCIAL SUPPORT

- Patients may lose social support due to changes in occupation, hobbies, relationships and in physical abilities.

**Ask the Question** – What social support/outlets do you have?

CARER NEED

- Carers need training in order to feel competent to help the patient.
- Important to check with a carer at every stage that they feel able to continue in their caring role.

**Ask the question** – What support do you have as a carer? Is there any additional support you feel would help?
DISEASE SPECIFIC SYMPTOMS/ISSUES

This section highlights the areas where there are significant symptoms pertaining to a particular disease that the professional needs to be aware of. The list is not exhaustive but will be a guide as to the differences.

MISDIAGNOSIS
- These neurological diseases are often difficult to diagnose in the early stages and have similarities. There are no definitive tests.
- Patients may have cognitive changes before they are correctly diagnosed, causing difficulties with advanced care planning and understanding of their condition.
- Patients with CBS, PSP and MSA do not usually respond to the medication used to treat Parkinson’s Disease.

PROGRESSIVE SUPRANUCLEAR PALSY
- Restricted downwards gaze.
- Frequent cause of falls.
- Lack of awareness of risk.
- Unpredictable, impulsive behaviour.

CORTICOBASAL SYNDROME
- May present as an asymmetric condition.
- Alien Hand Syndrome relatively common in CBS, may result in an inability to control the hand and a feeling that the limb is “alien”.

MULTIPLE SYSTEM ATROPHY
- Key symptoms include autonomic dysfunction, ataxia and Parkinsonism.
- Autonomic dysfunction, may present as postural hypotension, impotence, constipation, bladder dysfunction, difficulty maintaining correct body temperature, dry mouth or sleep disruption.

HUNTINGTON’S DISEASE
- HD is characterised by an excess of movement and a significant impact on mood and cognitive abilities.
- Enteral feeding can be problematic as patients may be more likely to either accidently remove the tube due to excess movement, or may try to remove it due to cognitive or psychiatric changes.
- Psychiatric changes can include disinhibition, a lack of insight into safety issues, non-compliance with suggested treatment and emotional lability.
- Significant psychological distress associated with the genetic nature of HD.
MOTOR NEURONE DISEASE

- There are several types of MND, the two main types of MND are Amyotrophic Lateral Sclerosis (ALS) and Progressive Bulbar Palsy (PBP).
- ALS affects the upper and lower motor neurones and is characterised by weakness in the limbs.
- PBP affects the speech and swallow first and has a shorter prognosis.
- Both ALS and PBP are rapidly progressive and need to have constant review.
**PSYCHOLOGICAL NEEDS**

**COGNITION**
Many patients with RPND will have early cognitive impairment. Timely assessment is key and a baseline assessment can be completed by any AHP – (see Appendix 3).

*Ask the question* – *Have you noticed any changes in your memory or other cognitive function?*

**All AHPs**
- Referral to clinical psychology for further assessment may be necessary.
- Early introduction of advanced care planning will enable patients to influence some choices further on in their disease progression (see appendix 1).
- Check mental capacity regularly.

**DEPRESSION**
This is more prevalent in patients with RPND. It needs to be considered & treated appropriately, not dismissed as an inevitable consequence of having a progressive condition. Depression will impact on the patient’s ability to take part in therapeutic intervention & therefore needs to be addressed. This group faces significant losses, for example the loss of a role in their family or working life.

*Ask the question* – *Have you seen any changes to your mood?*

**All AHPs**
- Report concerns regarding depression to your patient’s medical team.
- Refer to clinical psychology or community mental health teams.
PHYSICAL NEEDS

NUTRITION AND HYDRATION
Swallowing changes impact an individual’s ability to maintain appropriate nutrition and hydration. Physical changes, for example excessive salivation or drooling and loss of dexterity will affect the practicalities of eating, especially the length of time taken to eat and drink. The social element of eating and drinking can be markedly affected by the embarrassment resulting from feeding difficulties; texture changes to food and fluids and enteral feeding. These changes can greatly impact on the psychological well being of patients and family. Early discussions regarding the patient’s preferences for treatment if swallowing deteriorates can be helpful.

- Refer to a Dietitian as soon as swallowing is affecting the quantity and type of food/fluids taken or there is weight loss of 5-10% in a 3 month period.
- Refer to SaLT for regular assessment.
- Refer to a dietitian when enteral feeding is being considered rather than following tube placements.

Ask the Question – Have you been losing weight/have you noticed changes in how your clothes fit? Are you finding it difficult to eat or drink?

Dietetics
- Follow a normal nutritional plan but do not treat according to the MUST score (assessment tool) as rapid deterioration may cause changes to occur quickly. Do not decline referral for a patient with RPND if MUST score is too low, as they may need treatment earlier than other conditions.
- A realistic nutritional goal is likely to be to maintain current weight rather than aim for weight gain.
- Education of the patient and carer on the importance of nutrition is important as they may not perceive a nutritional problem.
- As discussed earlier, patients will need more regular review and to stay on a dietitian’s caseload.
- Patients can travel overseas if receiving enteral feeding – companies can pre-pack or deliver enough feeds to cover one overseas trip a year (depending on their policy).
- The dietitian should also be available at the end of a patient’s life to advise regarding changes in nutritional requirements, particularly if a patient is receiving enteral feeding.

Occupational Therapy
- Consider adapted cutlery, beakers and other aids at an early stage to maintain independence.
- Ensure carers are aware that food and drink needs to be within reach as the ability to reach out is often restricted.
- Consider the impact of fatigue on feeding and support the patient and their carer with fatigue management.
- Continence issues may impact on a patient’s willingness to maintain sufficient hydration, consider equipment to aid continence or referral to continence specialist for assessment.
Speech and Language Therapy

- Early planning for difficulty in maintaining safe swallow can prevent crises. Good communication skills are key in ensuring this conversation is effective whilst being aware of the impact of this on the patient.
- Consider “risk managed” feeding and comfort feeding only at the end of life and consider the implications of this on nutrition and hydration.
- Consider assessment of capacity, in line with the Mental Capacity Act (2007) when decisions around feeding are made.
- May need to consider a range of swallow assessments to ensure effective recommendations can be made. This may include videofluoroscopy, cough reflex testing, pulse oximetry, cervical auscultation and fiberoptic endoscopic examination of swallowing.
- Also consider use of standard swallow checklists to measure change in function over time.
- Regular review is necessary.
- Patients may need enteral feeding to meet fluid requirements, rather than due to unsafe swallowing of food.
- Oral care can be difficult to maintain. Work closely with dietitian to ensure balance between correct diet and maintaining oral care if the mechanics of eating become a problem eg pocketing.
- Consider independence at mealtimes, highlight safe feeding practices.

Physiotherapy and Occupational Therapy

- Consider positioning for correct feeding to support intervention by colleagues. Correct seating, neck supports and splinting may allow a patient to continue oral feeding rather than requiring enteral feeding.
- Dietitians require regular weight checks for this group of patients, however due to mobility problems this may be difficult. If you have access to scales, either on a hoist or in a treatment gym, it may be useful to weigh the patient during a treatment session and feed this back to a dietitian.
CONSTIPATION
This is a common problem, which may be due to changes in bowel motility, reduced overall mobility, lack of sufficient hydration or the effect of medications. It may cause pain and affect a patient’s tone and functional abilities.

Ask the Question – Are you opening your bowels regularly and easily?

Dietetics
- Be aware that a high fibre diet may not be effective due to motility issues.
- Check sufficient fluid intake.

Speech and Language Therapy
- Assess ability to take fluids and nutrition.

Complementary Therapy
- Consider massage, reflexology and acupuncture/pressure techniques to manage constipation issues.
- Teach carers the effective techniques for that patient for their ongoing management.

Physiotherapy and Occupational Therapy
- Activity will aid bowel motility – encourage upright exercise.
- Correct posture will aid the opening of the bowels – consider a patient’s posture on the toilet.
- Correct, upright posture at other times will also aid bowel motility.
SALIVATION
Most patients will present with excess saliva, but some may present with a dry mouth. This can impact on their ability to maintain effective nutrition and hydration and also their confidence in social situations. Saliva may also be too thick or too thin, rather than present or absent. This can be managed with medication or other management for example Botox, or the use of syringe driver to deliver medication & should be reported to the patient’s medical team if behavioural management techniques described below are not effective.
- A dental referral may be appropriate if this is contributing to the problem.
- Use Hyoscine with caution in MSA as it commonly causes hallucinations or confusion.

Ask the Question - Are you troubled by saliva or excessive dribbling?

Physiotherapy and Occupational Therapy
- Posture management can aid effective clearance of secretions.
- Ensure any aids the patient uses to help them manage their secretions are available and in reach.
- Adaptive splinting may enable the patient to wipe away secretions themselves.

Complementary Therapy
- Acupuncture/pressure can be effective for saliva management – consider treating with acupressure & teaching carers for ongoing management.

Speech and Language Therapy
- Ensure swallow is effective and advise on techniques to increase ability to swallow saliva.
- Consider behavioural solutions, such as oral exercises, head and body positioning, swallow reminder prompts and natural products such as grape juice.
COMMUNICATION
All professionals should be screening for communication difficulties & referring on. These changes may happen quickly and will progress further and can make it difficult for the patient to be fully involved in planning for their treatment and future care.

**Ask the question – Are you having difficulty making yourself understood?**

**Speech and Language Therapy**
- Use general communication aids, but reassess regularly, not every aid will last forever.
- Plan for deterioration, provide appropriate aids ahead of time to avoid crises and give a patient time to practice with the new aid, particularly if their cognition may deteriorate.
- Plan for being in different environments, patients with RPND may not be able to use all aids in all situations.
- Also consider “low tech” versus “high tech” communication aids, some may not be effective in different circumstances or may not be appropriate for all patients. It can be helpful for patients with a “high tech” communication aid to have a “low tech” back up in case of failure e.g. picture, alphabet board.
- Specialist Augmentive and Alternative Communication assessment may be available in some areas – ensure timely referral for this.
- Hospital admissions for patients using communication aids may be difficult. A “hospital passport” with details of how to aid someone’s communication may be useful.
- Consider language issues that may be associated with cognitive decline as well as dysarthria. This may include receptive as well as expressive language difficulty.
- Communicate in the right way for the right patient.
- Discuss and educate with regards to expected changes in communication, if appropriate. Don’t be afraid to be honest if asked.
- Look beyond intelligibility and consider tools such as the “Dysarthria interaction profile” (Bloch 2012).

**Occupational Therapy**
- Consider environmental controls well in advance, if the patient can cope with the idea, as the process can be long and they need time to familiarise themselves with the equipment. They can now be linked to much of the technology already in the home.
- Consider a patient’s ability to call for help.
- Consider impact of seating, supports and splinting on ability to use communication aids.

**Physiotherapy**
- Consider positioning for communication, both in a chair, wheelchair and in bed.
FATIGUE
Fatigue impacts on every other function and can be the most debilitating aspect of a patient’s condition. Cognitive changes might limit their ability to manage it, therefore carers need to be closely involved in fatigue management training. Other symptoms, such as excess movement or pain, may impact on sleep hygiene & therefore increase day time fatigue, as may respiratory problems or equipment.

Ask the Question – Do you feel a tiredness that isn’t relieved by sleep and is affecting your every day abilities?

Occupational Therapy
- Teach fatigue management strategies to patient and carers.
- Focus on prioritisation & negotiation with the patient and carers.
- Goals are likely to be to maintain current level of function rather than to improve.
- Plan ahead – provide equipment, plan for changes early and for the patient’s worst day.
- Consider sleep hygiene and how to manage this e.g. positioning; and its effect on depression.

Physiotherapy
- Design exercise plans taking into account the significant impact of fatigue.
- Discourage the phrase “use it or lose it” as this puts undue pressure on the patient and carers.
- Gentle exercise programmes can have a positive effect on fatigue.

Complementary Therapy
- Relaxation can reduce feelings of fatigue, use therapies which promote relaxation.
- Treatments aimed at improving sleep hygiene can also be helpful.
FUNCTION
A patient with RPND is likely to experience a rapid decline in their physical functioning. Ensure that you are aware of local and national services that may be able to provide assistance with provision or funding of specialist equipment. A list of organisations that may be able to help can be found in appendix 5.

Ask the Question – How are you managing with your day to day tasks?

Physiotherapy
- Weakness is usually very global for these patients. It is more useful to concentrate on assessment and treatment of overall function rather than specific muscle groups.
- Muscle strength is very unlikely to improve and placing focus on “strengthening” exercises can be very disheartening for the patient & their carers.
- Encourage patients who want to exercise to see achieving ADL tasks as maintenance.
- Involve carers, if appropriate, in activities such as stretching and correct positioning.
- The focus needs to be on overall quality of life rather than looking at specific activities.
- Consider orthotics, splinting and mobility aids early to prevent problems and enable patients to get used to them.
- Be particularly aware of the glenohumeral joint – it is highly prone to subluxation in these patients. Regular review of the position and health of this joint is imperative.
- Many patients will have difficulty maintaining head control. There are many different neck supports and collars available. Their provision needs careful consideration and may need referral on to Surgical Appliances. Collars are hard to get right and it may not be possible to achieve the “perfect” neck position for all patients.
- Take into account when planning activities that some patients may have abnormal sensation.
- Many patients will fall regularly and injuries can have a significant impact on a patient's functional ability. Regular review after a fall is important.
- Patients’ ability may be more significantly affected by other medical conditions, such as urinary or respiratory tract infections, than patients with other conditions. Regular review will ensure appropriate intervention.

Occupational Therapy
- Wheelchairs need to be planned ahead as seating requirements will be more complex and assessment for electric/tilt-in space wheelchairs is a longer process.
- Carry out manual handling risk assessment.
- Plan ahead for appropriate seating. Tilt in space and postural support are both likely to be necessary.
• Consider the psychological impact of equipment in the home – changes may happen very rapidly and not give patients and their carers sufficient time to cope with changes in lifestyle.
• Consider Social Care involvement for planning adaptations.
• Use charity funding/rental schemes to bridge gaps in the provision of equipment e.g. stairlift and to buy time to plan for more appropriate provision if needed. This can also help with the psychological adjustment to a rapidly changing situation and maintain normality for a while.

Complementary Therapy
• Complementary therapies can be useful in reducing areas of high tone and therefore improving function.

DRIVING
Every driver has a legal obligation to notify DVLA of any condition likely to affect them for longer than 3 months. They are also required to notify their insurance company or their insurance may be invalid, leaving them financially at risk.

Reduced reaction times, poor grip, decreased range of movement, poor head control, fatigue and cognitive problems will all have a bearing on someone’s ability to drive.

Ask the question – Would you be able to stop in an emergency? Is your ability to control the vehicle at all times as good as it was?

All AHPs
• Consider the impact of all changes including cognitive ones on the patient’s safety to continue driving – changes may happen very quickly and the patient may not have insight into their own safety.
• They can be referred to a Mobility Centre for Specialist Assessment with a therapist and driving instructor which can take away the doubt.
• Check access to benefits such as a “blue badge” to aid the patient’s ability to take part in social activities.
• Accessing transport requires manual handling risk assessment.
RESPIRATORY CHANGES
Some patients with RPND may experience significant respiratory changes associated with muscle weakness. Some patients may have very close monitoring of their respiratory functioning at a specialist centre but others may not.

Ask the Question – Have you noticed any changes to your breathing? Are you coughing more than usual? Do you have poor sleep?

All AHPs
- Have an awareness of the signs of respiratory impairment including:
  - Breathlessness
  - Orthopnoea
  - Recurrent chest infections
  - Disturbed sleep
  - Non-refreshing sleep
  - Nightmares
  - Daytime sleepiness
  - Poor concentration and/or memory
  - Confusion
  - Hallucinations
  - Morning headaches
  - Fatigue
  - Poor appetite
- Ask about frequency of chest infections or coughing.
- It may be necessary to have anticipatory antibiotics prescribed as these patients can decline very rapidly if treatment is delayed.
- Ensure you know which medical team is managing any respiratory complications or that the patient is referred for base line assessment.
- Ensure you are aware of any decisions that have been made about withdrawal of NIPPV, or management of chest infections if appropriate.

Physiotherapy
- Assess strength of cough and teach assisted cough to carers and patients if necessary – carers may need to do this due to the patient’s functional difficulties.
- Give breathlessness management advice, including anxiety management early in course of disease.
- If a patient is on NIPPV, discuss future withdrawal if not discussed elsewhere.
PAIN
Patients may have physical pain caused by movement difficulties or muscle spasm and may be affected by total pain. Total pain was defined by Dame Cicely Saunders as the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles. A patient whose pain cannot be managed by their general practitioner or nursing team should be referred either to a specialist pain team or to a palliative care team.

Ask the Question – Do you experience any pain, feel it is not effectively controlled or that you are not coping with it?

Complementary Therapy
- Complementary therapy can be targeted to treat a specific area of pain using, for example, massage or reflexology.
- It can also be used to treat total pain by improving patient's relaxation and sense of overall wellbeing.

Physiotherapy and Occupational Therapy
- Consider if positioning is adding to the pain and what measures could assist – specialised seating, postural support.
- Consider using TENS.

PRESSURE AREAS
Patients with RPND are at risk of developing pressure sores, as will anyone who is immobile for extended periods of time. However they may be more at risk of developing sores in unusual areas, such as the nose (if using NIPPV), the ears, elbows or around catheter bags. This may also be exacerbated by the fact that patients may have altered sensation and may not feel the pain of a developing sore. Referral to a tissue viability nurse may be useful.

Ask the Question – Do you have any red, sore or broken areas of skin?

All AHPs
- Check assessment is carried out regularly by nurses especially when sore areas are identified.
- Ensure good nutrition is maintained as this is important for good skin integrity.
- Organise pressure relieving equipment as appropriate.
INTIMACY
Patients' intimate relationships may be affected by changes in libido, body image, by the physical limitations their condition may impose or by psychological distress of patient or partner. If patients report a change to libido that is bothering them, referral to the medical team is important.
Some patients with RPND may experience some disinhibition. It is important to be aware of this when planning care to ensure no difficulties arise for the patient, carers or professionals.
Whilst it is important to be open to these discussions, it is also vital to be aware of cultural restrictions when discussing intimacy and sexuality.
There may also be issues around safeguarding.

Ask the Question – Is your condition affecting your intimate relationships? Have things changed in the physical relationship between you and your partner?

Physiotherapy
• Provide guidance with regard to positioning if physical limitations are impacting on intimate relationships.

Occupational Therapy
• Be aware of the impact different equipment may have on a patient and their partner’s ability to be intimate – for example single profiling beds or single seater armchairs can limit body contact between a patient and their partner.
• Use the discussion about beds to broach the subject of intimacy.
• It is important to facilitate closeness and touch.

Complementary Therapy
• Teaching simple hand or foot massage techniques can aid body contact between a patient and their partner and relax them both.
EMOTIONAL NEEDS

EMOTIONAL DISTRESS
Loss of hope, fear, lack of control, anxiety and frustration are just some of the emotions that a patient with RPND may be experiencing. All of these will affect the patient’s other holistic needs.

Movement disorders and neurological disease carry significant meaning in some cultures and this can impact on management.

Ask the question – Are you feeling anxious or out of control?

All AHPs
- Distress is likely to vary throughout the course of the disease and patients should be referred for counselling, via their General Practitioner or Hospice when distress is high.
- Assessment of emotional distress, with a tool such as the Distress Thermometer or the Hospital Anxiety and Distress Scale (see appendix 6) will enable identification of how anxious or distressed the patient is, as well as providing an initial screening tool for depression.
- If distress or anxiety are particularly high, they may require medication or referral to Mental Health teams. This should be discussed with the patient’s general practitioner.
- Ensure the patient and their carer, have an appropriate level of information about their condition and the intervention you are proposing.
- Be guided by the patient and carer’s preferences for how much information they would like.
- Education can only be effective if a patient’s anxiety is managed.

Occupational Therapy
- Teach anxiety management techniques to both the carer and the patient.
- Interventions such as therapeutic art, creative writing or reminiscence activity may help a patient to manage their distress by improving their feelings of self worth and from having a sense of achievement when they had given up hope.
- Careful assessment of a patient’s ability will be required and intervention should be designed according to this with assistive technology if necessary.

Complementary Therapy
- Complementary therapy can be absolutely key in managing emotional distress.
- Both the physical intervention and the relationship developed with a therapist over time can be beneficial in reducing distress and feelings of hopelessness.
PRIVACY
Patients with RPND can experience a significant loss of privacy due to their level of dependency, their loss of hand function and/or communication resulting in them needing a high level of personal care and the need for multiple visits by different professionals.

All AHPs

- Inform the patient why these visits are important.
- Negotiate visits, ask for permission to enter the home, respect the individual’s right to choice.
- Whenever possible, acceptable and beneficial to the patient, organise joint visits with other professionals. These are both good for the patient as they reduce visits and demonstrate joined up working, but also for the clinician as they can be a learning opportunity.
- Avoid duplication and liaise frequently with other members of the MDT.
- Try to ensure consistency. It is particularly important for this patient group to see the same professional on subsequent visits. It will give confidence to the patient to see someone familiar, particularly when there are cognitive changes, but a professional who has seen a patient before is also more likely to notice subtle changes in their condition.
SPIRITUAL NEEDS

Spirituality may be a significant issue for patients with RPND as they are facing rapidly progressive disease and imminent death. An awareness of the impact of this is important as it may over ride all other symptoms.

*Ask the Question* – What helps you cope with all that is going on for you right now?

**All AHPs**
- Be prepared for questions such as, “Why me?” – patients do not necessarily expect you to have an answer – a medical response to this question is not usually helpful; simply a listening ear is what is required.
- Value the importance of spiritual distress, listen to people’s concerns.
- AHPs will often have more time to spend with patients than medical staff and you may therefore develop a relationship which then allows a patient to be open to discussing spiritual concerns. Trust is important for these discussions.
- Questions regarding assisted suicide are more frequent in patients with RPND. It is important to be aware of current legislation and media coverage and to be prepared to deal with these questions.
- Facing a life limiting disease can cause people to question long held religious beliefs – be ready to offer support or refer on to appropriate religious leaders or chaplaincy services.
- Be aware of the grieving process – patients and their carers may be grieving for the life they will not have. Carers may also start to go through the loss of their loved one prior to their death especially where there is cognitive decline. Be aware of the impact this may have on their ability to fulfil the caring role.

**Occupational Therapy**
- Facilitate meaningful experiences through therapeutic activity or organising trips to special places.
- Enable access to organised religion if relevant.

**Complementary Therapy**
- The deep relaxation associated with complementary therapy may be a spiritual experience for some. Be ready to listen to spiritual concerns if they arise.
FINANCIAL NEEDS

Patients may have significant financial concerns and these may impact negatively on their experiences.

All AHPs should be aware of local or national organisations that may be able to give advice, such as the Citizens Advice Bureau or national charities. A basic knowledge of benefits that may be available to patients with RPND is also helpful – the latest information on this is available on government websites.

Some patients may still be working at an early stage of their disease and all AHPs should be aware of the support with “Access to work”, whether this be with supportive seating, communication aids or specialist computer equipment.

Ask the Question – Do you have any financial concerns?
SOCIAL NEEDS

HOUSING
Patients’ physical condition may necessitate changes in housing, or major adaptations to housing. This can take time and therefore forward planning is necessary. This can be a hugely stressful time for patients already in a difficult situation and all professionals should support with this. Carefully worded supportive letters from AHPs, detailing the patient’s current and future needs, as well as the likely course of the disease can be helpful in expediting applications.

**Ask the Question** – Is your current housing suitable for your needs?

**All AHPs**
- Consider referral to Social Care where necessary for assistance with adaptations.

SOCIAL SUPPORT
Patients may lose their social support due to changes in occupation, hobbies, relationships and in their physical abilities. It is common for patients to become socially isolated, which can then impact on their physical and psychological well being.

**Ask the Question** – What social support/outlets do you have?

**All AHPs**
- Consider referring the patient to Hospice Day Therapy services or other day centre to facilitate social integration.
- Give information on accessible community groups or disease specific groups – it is important to highlight to patients that they may meet people with more advanced disease than themselves and help them to consider how this would affect them.
- Direct people to useful sources of information – well known websites, leaflets, social networking groups etc.
- Consider referring patients to charities who will fund special days, treats or holidays for those affected by neurological conditions.

**Occupational Therapy**
- Encourage patients to look at other ways of doing hobbies/activities.
- Encourage patients and their carers to learn new skills within their abilities.
- Patients may need significant help with learning to accept, adapt and achieve.
CARER NEEDS

Carers, both informal and professional, need training in order to feel competent to help the patient. However it is important to balance the carer’s need for information with over-burdening them. Some informal carers are able to take on a lot of medical management of their loved one, others may not and that can vary over time. It is important to check with a carer at every stage that they feel able to continue in their caring role.

Ask the question – What support do you have as a carer? Is there any additional support you feel would help?

All AHPs
- Involve carers in discussions with regard to care packages, especially health funding.
- Encourage carers to request carer assessment from Social Care if required which should enable the carer to have access to support.
- Refer for carer support with Hospice services.
- Identify and discuss with the patient and carer if respite is required and facilitate this if necessary.

Physiotherapy and Occupational Therapy
- Provide moving and handling training, appropriate to the level of need of the patient.
- Provide training in the use of moving and handling equipment.
- Provide training in the management of respiratory complications, including the signs to look for indicating respiratory distress.
- Consider suggesting the carer has First Aid training to give them confidence that they will know how to deal with any respiratory emergencies.

Speech and Language Therapy
- Teach safe swallow strategies
- Give thorough teaching on grades of thickened fluids and types of diet
- Educate and support on the use of communication aids and communication strategies.
- Where relevant, explain what “risk feeding” is and the implications of this.
- Avoid generic information on feeding strategies but give specific written instruction.
- Consider signposting to Basic Life Support Training, for example courses run by St John’s Ambulance or the Red Cross which will cover what to do when someone is choking. This can give carers confidence that they are equipped with the right skills for this circumstance.

Dietitian
- Give food fortification training.
- Discuss with the carer regarding early provision of supplements and the reasons for this.
- Discuss using smaller meals to encourage patients to eat and reducing the pressure on the patient to eat.
PSYCHOLOGICAL SUPPORT
Carers may be suffering the same psychological distress as patients and may need the same degree of support.

Referral for counselling via their GP, or to carers groups run by hospices or community groups may be useful. Be aware of local services. Some hospices have carer support services for both individuals and in groups.

Complementary Therapy
- Can be supportive and also gives therapeutic time out.
- Massage can relieve strained or tense muscles.
The focus of treatment will be different at the end of life and medical management may take more of a key role.

However it may be important to the patient and their carer that an AHP that has been involved in their care, particularly if a relationship has been built up over some time, continues to be there to give supportive care. This may also improve the carer’s bereavement journey.

A number of issues can arise at end of life for patients with RPND that may be different from patients dying from other conditions.

- Questions such as when and how to stop NIPPV, tube feeding and hydration can be difficult ethical dilemmas. Many acute hospitals and primary care teams will have an Ethics team who may be able to support the multidisciplinary team in particularly difficult cases.
- Patients, carers and professionals may also have to consider whether to treat infections or not and establish a “ceiling of care”.
- Discuss the patient’s preferred place of care, whether they would like hospital admission, hospice care or support in the home, as well as preferred place of death.
- Consider important discussions regarding ‘Do not attempt cardiopulmonary resuscitation’ and ensure that the outcome of these discussions is clearly communicated to all those involved in the patients care. Ensure patient held DNACPR forms are completed as appropriate.
- Be aware of any Advanced Decisions to Refuse Treatment that may be in place, and ensure these are shared with all colleagues involved in the patients care. It is important to have a good understanding of the legalities of these documents as patients may ask their AHP to help them complete an ADRT (see appendix 1).
- It is important to involve Palliative Care specialists in these decisions and for the conversations to be held at an early stage.
- Communication may become almost impossible apart from minimal indication of yes and no e.g. by a movement of the eyes.

Some areas are using a system called “Co-ordinate my Care”, which is a centrally held record of key decisions the patient has made, as well as important medical information. It is vital to ensure familiarity with this if it is in place locally.

It is important to be familiar with local bereavement support services, which may be offered from the local hospice so that a distressed family member can be directed to the appropriate professionals/groups.
DISEASE SPECIFIC SYMPTOMS/ISSUES

This section highlights the areas where there are significant symptoms pertaining to a particular disease that the professional needs to be aware of. The list is not exhaustive but will be a guide as to the differences.

MISDIAGNOSIS

These neurological diseases are often difficult to diagnose in the early stages and have similarities. There are no definitive tests.

Patients with CBS, MSA and PSP are often misdiagnosed initially with Parkinson’s Disease, then as the disease progresses or different symptoms arise, the diagnosis is changed. Patients with MND also frequently have a late diagnosis and may be told their condition is something more benign as an original diagnosis. Patients are often fairly advanced in their disease by the time they have an accurate diagnosis, which can prevent early planning and involvement of appropriate services and increases the level of distress at being given the news.

Patients may have cognitive changes before they are correctly diagnosed, causing difficulties with advanced care planning and understanding of their condition.

Patients with CBS and PSP do not usually respond to the medication used to treat Parkinson’s Disease, although there may initially be some benefit (which confuses and delays the diagnosis). There can be anxiety associated with the withdrawal of this medication that AHPs should be aware of and be ready to support with.

For those with MSA about a third will get some benefit from the medication but it is not as effective as for PD and does not last as long. It is often used up to the end of life for relief of muscle rigidity.

PROGRESSIVE SUPRANUCLEAR PALSY

- Impulsivity – important symptom.
- Lack of awareness of risk.
- Unpredictable behaviour – all these make leaving the patient alone a problem for carers in any setting.
- Patients with PSP will frequently have difficulties with vision that patients with other RPND do not have. The significant symptom is restricted downward gaze (dirty tie syndrome), causing difficulty on stairs, kerbs etc., following words on a page when reading, eye tracking. Falls can often be caused by an inability to look down to check the path is clear. This needs to be taken into account when developing falls prevention programmes.
- Referral to an optician or a neurologist, or provision of “prism” glasses can be useful to improve a patient’s visual field.
- Backward falls is an early symptom and falls in general due to poor motor planning.
- Axial rigidity – throwing themselves back into the chair rather than bending to sit.
- Palilalia/echolalia – repetition of words or phrases.
- Breathy voice.
- Unintelligible speech is first motor symptom in (red flag indicator).
- Mouth stuffing/pocketing - over filling mouth often leading to choking.
- Photosensitivity.
- Deal with one subject at a time and give simple instructions.

### CORTICOBASAL SYNDROME

- CBS may present as an asymmetric condition, whereas the other RPND are usually more symmetrical. This can sometimes cause a misdiagnosis of stroke, resulting in a late true diagnosis.
- Alien Hand Syndrome is also relatively common in CBS, and may result in an inability to control the hand and a feeling that the limb is “alien”. These movements occur in response to external stimuli and do not usually occur spontaneously. Therefore management aimed at reducing the stimulus to the affected hand can be of benefit in reducing this symptom. It is also important to recognise that in some patients, the hand may follow external stimuli, such as the moving hand of a practitioner and that this is out of control of the patient.

### MULTIPLE SYSTEM ATROPHY

- There are three different symptoms of this disease and people may present with any combination of them however there **must** be the first one for a diagnosis of MSA to be made.
  - Autonomic dysfunction
  - Ataxia
  - Parkinsonism
- The Autonomic dysfunction may present as postural hypotension, bladder dysfunction, impotence/erectile dysfunction, constipation, difficulty maintaining correct body temperature, dry mouth or sleep disruption. Whilst these symptoms cannot be managed by AHPs, their presence can impact on the patient's ability to take part in therapeutic intervention and activities of daily living.
- Due to the autonomic dysfunction people with MSA are often asymptomatic when they have infections. A sudden deterioration may indicate the presence of infection and early intervention with antibiotics is important.
- Certain PD medication is best avoided for MSA patients. (see information on MSA website).

### HUNTINGTON’S DISEASE
• HD is characterised by an excess of movement and a significant impact on mood and cognitive abilities.
• Patients with HD will have very high energy requirements due to the excess movement and are at greater risk of not meeting their nutritional needs, therefore early involvement of dietitians and provision of nutritional supplements is key.
• Assessment for enteral feeding can also be more ethically challenging as it may be required due to cognitive or practical requirements, rather than the lack of ability to swallow.
• Provision of enteral feeding can be problematic as patients may be more likely to either accidently remove the tube due to excess movement, or may try to remove it due to cognitive or psychiatric changes.
• Early involvement of expert clinicians is important – most patients with HD will be in touch with a specialist centre and it is advised to contact them for advice on managing feeding.
• Psychiatric changes, combined with cognitive difficulties can lead to a number of potentially challenging behaviours. These can include disinhibition, a lack of insight into safety issues, non-compliance with suggested treatment and emotional lability.
• It is recommended that early involvement with clinical psychology at an HD specialist centre is initiated, as well as early advanced care planning to ensure patient preferences can be taken into account.
• Patients can live with HD for longer than some of the other conditions.
• They are likely to be diagnosed earlier due to the family history of the condition.
• The disease trajectory is also harder to predict than the other RPND and therefore care may be more episodic. It is important to have a system for regular review in place, or for the patient to know who to contact if they have concerns, to ensure any new problems do not get missed.
• There can be significant psychological distress associated with the genetic nature of HD. There may be concern about passing the condition on to children, or anger that they have inherited this disease from a parent. Some people have lived for many years with the knowledge they could get HD and have seen parents or other relatives die from the condition. Patients are also likely to have younger children as it usually affects people at a slightly younger age than the other conditions. Again, early involvement of clinical psychology and genetic counselling is vital to try to address these concerns. This can be accessed at the HD specialist centres.
• There are specialist HD advisors for each region, their contact details can be found on the HDA website (details in Appendix 4)

MOTOR NEURONE DISEASE
• There are several types of MND, with different disease trajectories.
• The two main types of MND are Amyotrophic Lateral Sclerosis (ALS) and Progressive Bulbar Palsy (PBP).
• ALS affects the upper and lower motor neurones and is characterised by weakness in the limbs. Patients with ALS will tend to get speech, swallow and breathing difficulties late in the course of their disease.
• PBP affects the speech and swallow first and has a shorter prognosis.
• It helps to be aware of the type of MND the patient has to be able to plan for their future care more effectively.
• Early involvement of Dietitians and Speech and Language therapists is particularly important in PBP.
• Physiotherapists and Occupational Therapists may be more involved in the early stages of ALS.
• It is important that the right AHP is acting as Key Worker for the patient.
• Both ALS and PBP are rapidly progressive and particularly need to have constant review
• It is particularly noticeable in patients with MND that a lack of forward planning significantly adversely affects a patient’s experience of the disease.
• Patients can have very complex needs with MND, but funding for professional input can be hard to secure.
• It is important for AHPs to work closely with nursing teams when seeking funding through Continuing Health Care to ensure the correct support for these patients.
• The Motor Neurone Disease Association is particularly supportive with funding applications for pieces of specialist equipment or other financial support as well as individual support and advice for families and professionals. Their details can be found in Appendix 4.
Appendix 1

Advance Care Planning Document

The Advance Care Planning – a guide for Health & Social Care staff is an 18 page document, advising how to approach this area. www.ncpc.org.uk/publication/advance-care-planning-guide-health-and-social-care-staff

See also: www.endoflifecareforadults.nhs.uk

Several areas have produced a document that includes all decisions about someone’s future and keeps it in one place.

“Planning for your future care” (Advance Care Planning) is a document produced by several agencies in the East of England which includes:

Introduction, including about Mental Capacity
Part 1. “About Me”. Description of patient, illness, who looks after me and important contact details.
Part 2. “Things I want people to know”. Things that are important about patient and their care.
Part 3. “About my care and treatment preferences”. PPC, Lasting Power of Attorney, Advance Decision Making and review, putting your affairs in order, making a will, DNAR. A copy can be given to the GP and Consultant of the advance decision to refuse treatment

It is designed to be completed over a period of time with the patient, carer and family.
Appendix 2

Examples of good practice

1. MDT (Farleigh Hospice)

Farleigh Hospice hosts the monthly meeting of the Mid Essex Neurological Group. This meeting is open to any professional working with patients with complex neurological diseases and at any one time may have Community Matrons, OTs PT’s, SaLTs, Dietitians, Doctors, Clinical Nurse Specialists or representatives from voluntary agencies attending. It is a 2 hour meeting usually at lunchtime and discusses any patients known to the professionals attending. Minutes are sent round so that those not attending are aware of issues. The intention is to send a summary to the GP to include them in the discussion.

It also acts as a focus for developments for these patients as it often highlights areas of concern or gaps in services.

It has also ensured collaborative working across organisations and provided a more seamless transition of care for patients across NHS, Social care and voluntary organisations.

As part of this work a Directory of Neurological Services in Mid Essex was compiled and sent to all services in the area which has been a good base line in service mapping.

2. Neuro Group CT (St Josephs Hospice)

The neurological support group (NSG), launched in January 2011, meets fortnightly on a Monday 11:00-15:00 in Finding Space at St Joseph’s Hospice in Hackney, East London. The NSG is designed to support people with progressive neurological conditions their carers and family. The focus of the group is to provide complementary therapies, such as acupuncture, massage, reflexology and reiki in an environment where social relationships and sharing experiences can flourish. The group is facilitated by the complementary therapies coordinator and run by volunteers; professional complementary therapists, volunteer befrienders and administrators, and a senior health care assistant (HCA). Hot refreshments and lunch are provided free of charge and attendees can self refer.

Quote from an MND patient “When I first came to the group people were very friendly and attended to me. Giving information, I didn’t know much about MND when I first came. My condition wasn’t explained to me by my GP. I like coming for massage and acupuncture. You can always talk to people about how my condition is changing. I like the environment, a really friendly place”. RS

For more information contact the complementary therapies administration team 0208 525 3144.
For professional or self referrals: First Contact Team 0300 30 30 400
Appendix 3
Assessment for Cognitive Impairment for MND

Edinburgh Cognitive and Behavioural ALS Screen (English Version 2013)
https://www.era.lib.ed.ac.uk/handle/1842/6592

The ECAS is a practical screening tool that incorporates a range of short cognitive tests that have been shown to be sensitive to cognitive impairment in ALS. The ECAS has been designed to differentiate between the different profiles common with ageing including depression, Alzheimer’s disease and Fronto-Temporal Dementia. Executive Functions, Memory, Language, Visuo-Spatial skills and Social cognition are specifically assessed whilst a Behavioural and Psychosis brief interview can be carried out with carers or relatives. The ECAS is designed for ALS patients and answers can be given verbally, or by a combination of writing or pointing. It is suitable for patients who are anarthric or patients who have no hand motor function. The total score is 136 points and should take no longer than 15 minutes to administer.

The Montreal Cognitive Assessment (MoCA)
(Dr Z Nasreddine 1996)
www.mocatest.org

The Montreal Cognitive Assessment was validated in the setting of mild cognitive impairment. It is a one page 30 point test administered in approximately 10 minutes. It assesses several cognitive domains: memory recall; visuo-spatial ability; aspects of executive functioning; language and orientation in time and place.
**Appendix 4**

Organisations that may be able to help (with funding, information, etc)

These organisations often have local support groups, specialist support workers and sometimes give financial help

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Address</th>
<th>Tel:</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PSP Association (Progressive Supranuclear Palsy) &amp; CBS (Corticobasal Syndrome)</strong></td>
<td>167 Watling Street West, Towcester, Northamptonshire NN12 6BX</td>
<td>0300 0110 122 (Helpline) 01327 332410</td>
<td><a href="http://www.pspassociation.org.uk">www.pspassociation.org.uk</a></td>
</tr>
<tr>
<td><strong>MSA Trust (Multiple System Atrophy)</strong></td>
<td>Southbank House, Place Prince Road, London SE1 7SJ</td>
<td>020 7940 4666</td>
<td><a href="http://www.msatrust.org.uk">www.msatrust.org.uk</a></td>
</tr>
<tr>
<td><strong>Huntington’s Disease Association</strong></td>
<td>Head Office, Suite 24, Liverpool Science Park, Innovation Centre 1, 131 Mount Pleasant, Liverpool L3 5TF</td>
<td>0151 331 5444</td>
<td><a href="http://www.hda.org.uk">www.hda.org.uk</a></td>
</tr>
<tr>
<td><strong>MND Association (Motor Neurone Disease)</strong></td>
<td>PO Box 246, Northampton NN1 2PR</td>
<td>0845 762 6262</td>
<td><a href="http://www.mndassociation.org">www.mndassociation.org</a></td>
</tr>
<tr>
<td><strong>Local Hospices</strong></td>
<td></td>
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<td><a href="http://www.helpthehospices.org.uk">www.helpthehospices.org.uk</a>  Search: ‘Find a hospice’</td>
</tr>
</tbody>
</table>
Appendix 5
Tools for measuring mood

**Distress Thermometer (West London Network – Hillingdon)**
The patient circles a number between 0-10 that best describes how much distress they have been experiencing in the past week.

The patient also indicates from a list anything that has been a problem in the last week.

**HAD (Hospital Anxiety and Depression) Scale (Zigmond & Snaith 1983)**
Used to determine the levels of anxiety and depression that a patient, who has physical health problems, is experiencing.

It is a 14 item scale (7 for anxiety and 7 for depression).

It is scored from 0-3
References


Nasreddine, Dr Z (1996) *The Montreal Cognitive Assessment (MoCA)*

Zigmond and Snaith (1983) *HAD (Hospital Anxiety and Depression Scale)*

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