

## Chapter 2

# End of Life Care in Neurological Disease

David Oliver and Eli Silber

**Abstract** Neurological disease may present and progress in many different ways, according to the disease and the individual, and presents a challenge for care throughout the disease progression and particularly at the end of life. These issues include the variability of disease progression, associated cognitive change, complex treatments, and the concerns and problems encountered with inherited diseases. The use of triggers to identify deterioration and the possibility of end of life may be useful in allowing the most appropriate care to be provided, enabling the patient and family to maintain their quality of life.

**Keywords** Triggers • Palliative care • Recognition of end of life

### Case Vignette

Jean was 75 years old and married. She had been diagnosed with Parkinson's disease over 10 years ago but had slowly deteriorated. Her mobility was restricted, and she could only leave the house with help. She was finding eating more difficult, as she could not cook for herself and her swallowing had worsened. She was admitted to hospital on two occasions, following falls at home, but was discharged within 2 days.

On the next occasion, she fell at home and was admitted to hospital. Her condition deteriorated, as she was unable to receive her medication on time. She was restricted to bed but was determined to go home. On discharge, she accepted extra help, but her husband became very tired and found caring for

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her more difficult. She was readmitted to hospital and died 2 days later. Her husband and family were shocked, as they had not realized that she was near to the end of her life and had not discussed her wishes with her. They expressed surprise that no health professional had talked of her dying and felt that if they had realized, they would have talked more to her and tried to keep her at home, where she had wished to be.

The care of people with progressive neurological disease provides considerable challenges for clinicians in neurology and palliative care. Neurological diseases offer unique complexities, and while many will share similarities, there are also considerable differences depending on the specific diagnosis. Even in similar conditions, there is considerable variability in the rate of progression, resultant symptoms, and other complications that may ensue. The considerable differences in the rates of progression within the same disease process, and the fact that there are limited biomarkers make prognostication particularly challenging. Thus, there will be great variation as every person is an individual and present with the disease and progress in their own individual particular way.

Neurological diseases have many causes and manifest in very different ways (see Table 2.1).

The main progressive neurological diseases requiring palliative care input are:

- Motor neurone disease
- Multiple sclerosis
- Parkinson's disease and associated diseases:
  - Progressive supranuclear palsy
  - Multiple system atrophy
- Huntington's disease

Neurological services may not always be involved in the diagnosis or ongoing care of people with neurological disease, as acute episodes due to deterioration may be admitted to hospital under the care of other specialities or remain under primary care at home. For instance, stroke is an important acute neurological disease where end of life issues may be of importance, as many patients die acutely in the first episode or are left with severe disability and may deteriorate later, but in the UK, patients are often cared for in stroke units by specialized stroke physicians rather than by neurological services. In most developed countries, brain tumors are also cared for primarily by neurological services, whereas in the UK, the care of this group is primarily within neurosurgical and oncological services. In the majority of developed countries, neurology services are involved in the care of people with dementia, whereas in others, the primary responsibility for directing care is in elderly care or elderly mental care services.

The incidence and prevalence of these diseases varies but overall the numbers of patients requiring care is high. The requirements of care are large and develop over a longer period of time. In England, these common neurological conditions have the

**Table 2.1** Diseases of the nervous system that may require palliative care

|                                  |  |
|----------------------------------|--|
| <i>Central nervous system</i>    |  |
| Immune                           | Multiple sclerosis<br>Devic's disease  |
| Infection                        | HIV<br>Creutzfeldt-Jakob disease<br>Subacute sclerosing panencephalitis  |
| Degenerative                     | Motor neurone disease<br>Parkinson's disease<br>Progressive supranuclear palsy<br>Multiple system atrophy<br>Alzheimer's disease and other dementias including frontotemporal (Pick's) |
| Inherited                        | Cerebellar degenerations<br>Huntington's disease<br>Inherited cerebellar ataxias<br>(Autosomal dominant – SCAs and recessive Friedreich's ataxia)                                      |
| Vascular                         | Stroke (infarction and hemorrhage)<br>Subarachnoid hemorrhage  |
| Severe acute acquired injury     | Hypoxia<br>Traumatic – brain and spinal injury   |
| Neoplastic                       | Primary brain tumors<br>Metastatic disease<br>Paraneoplastic syndromes (cerebellar, limbic encephalitis)   |
| <i>Peripheral nervous system</i> |  |
| Anterior horn cell disease       | Postpolio syndrome   |
| Peripheral nerve disease         | Inherited – Charcot-Marie-Tooth disease<br>Amyloid<br>Inflammatory – Guillain-Barre/CIDP<br>Paraneoplastic neuropathies<br>Neuropathies associated with chronic conditions             |
| Neuromuscular junction disease   | Lambert-Eaton syndrome<br>Myasthenia gravis  |
| Muscle disease                   | Inherited dystrophies (e.g., Duchenne muscular dystrophy)<br>Inherited myopathies  |

following prevalence and total numbers of patients and account for these numbers of deaths:

|                                | Prevalence      | Estimated numbers <sup>a</sup> | Annual deaths <sup>b</sup> |
|--------------------------------|-----------------|--------------------------------|----------------------------|
| Parkinson's disease            | 110–180/100,000 | 120,000                        | 7,700                      |
| Multiple sclerosis             | 110–140/100,000 | 100,000                        | 1,500                      |
| Motor neurone disease          | 6/100,000       | 5,000                          | 1,500                      |
| Huntington's disease           | 6–10/100,000    | 5,000                          | 240                        |
| Multiple system atrophy        | 5/100,000       | 4,500                          | 200                        |
| Progressive supranuclear palsy | 6/100,000       | 5,000                          | 310                        |

<sup>a</sup>Assuming England of population 50 million

<sup>b</sup>The condition is mentioned on the ONS return from the death certificates during the period 2002–2010 [1]

## Clinical Approach to Palliative Care for Neurological Patients

The specific needs of neurological patients will vary according to diagnosis, stage of progression, and individual characteristics. However, there are some needs and concerns that will be common to many patients and their families, particularly at the end of life. There will be similarities across disease groups in the issues faced, and will require a palliative care approach. The World Health Organization defines palliative care as:

An approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [2]

Moreover, The UK National End of Life Care Strategy [3] suggests a pathway for end of life care comprising six steps – see Chap. 2 page x. Neurological diseases are included in the chronic illnesses considered within the strategy [3]. The strategy also stresses that people at the end of life should have access to:

- The opportunity to discuss needs and preferences and record them in a care plan
- Coordinated care and support
- Rapid specialist advice and assessment
- High-quality care and support during the last days of life
- Services which treat people with dignity and respect before and after death
- Appropriate advice and support for carers at every stage

These ideals are still being developed but challenge all services involved in the care of patients with progressive disease.

Neurological diseases have considerable differences in their care and support compared to other advancing disease – in particular cancer, which is often considered the basis of the palliative care approach. The main differences are:

1. The broad spectrum of neurological conditions leading to the challenges of diagnosis – which may be delayed and lead to advanced disease at the time of diagnosis and prognosis.
2. Variable rate of progression.
3. Mixture of cognitive and physical disability.
4. The overlap between physical, communication, cognitive, and mental health issues resulting in considerable management challenges.
5. Complex diseases, in some the diagnosis may be difficult and delayed because of an inability to biopsy and no clear biomarkers.
6. Some neurological conditions are inherited affecting the responses and concerns of families.
7. Recognition of end of life care. Many patients can live with severe disability for some time, and it may be difficult to recognize when palliative care is required.

There are a large number of neurological disorders; in most, palliative care is unnecessary and inappropriate, and in others, it is important.

## Variability in Progression

Neurological conditions are widely variable, and thus planning end of life care can prove challenging.

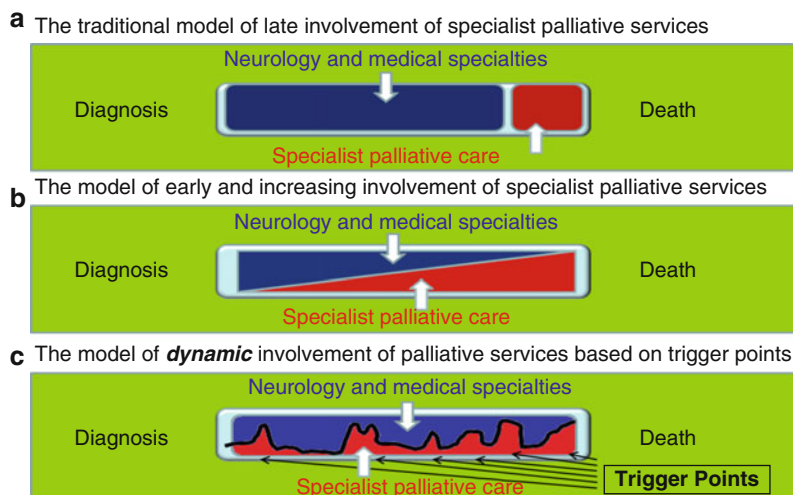
The changes may be:

- Acute onset, death, or variable recovery – as in stroke or trauma
- Rapid decline over months/a few years – such as MND
- Prolonged deterioration over several years – Huntington's disease, Parkinson's disease, PSP, and MSA
- Fluctuating condition with variable needs – such as MS

In some patients, the requirement for palliative care is both inevitable and fairly rapid, and in others, only a minority will require specialist palliative care on a longer term basis but may require care at the end of life. The progressive nature and the limited prognosis of motor neurone disease will often mean that it is appropriate to involve and plan palliative care from the time of diagnosis [4]. However, for some conditions, although they are progressive, the rate of progression may vary from months to decades. For instance, for the primary degenerative conditions such as Parkinson's disease or multiple sclerosis, the prognosis is generally good with only a limited average effect on longevity, but palliative care input may be required for those with a particularly severe disease course and when there is a final deterioration at the very end of life. For some diseases, the requirements are almost inevitable, and in others, only the most severely affected patients may require palliative care.

It is helpful to make a distinction between palliative care skills that should be part of the repertoire of all GPs, physicians, and neurologists, particularly those with an interest in the management of patients with chronic conditions, and specialist palliative care, which may be required for more complex and difficult situations – complex symptom management issues or psychosocial issues. It is also recognized that in the management of people with advanced neurological conditions, the neurologist may have specific and essential knowledge and skills, such as in the management of spasticity, adjustment of Parkinson's medication, and treatment of autonomic dysfunction, making their input valuable even when the patients are in the later stages of disease progression. End of life for neurological patients therefore almost inevitably requires the collaboration of those with expertise in palliative care working with those with neurological expertise (neurologists, elderly care physicians, rehabilitation consultants, psychiatrists, and nurse specialists) if the quality of life for people with neurological conditions is to be maximized.

New attitudes to patient autonomy and new ways of team working may be needed to ensure that patients' wishes are central to care plans and that each member of the team is clear about their roles and responsibilities. In comparison to palliative care for



**Fig. 2.1** Palliative care services and involvement in neurological disease (Taken from Bede et al. [6])

terminal cancer patients, as the person's needs vary over time, there may be a role for episodic involvement of palliative care services during the progression of the disease. This may occur at times of particular distressing symptoms, when patients face change or when psychosocial issues arise. Such times include diagnosis, the commencement of an intervention such as gastrostomy or ventilator support, or at the very end of life. This may be a challenge for all concerned, to ensure that coordinated care is maintained with good communication among the various professionals involved.

This change in involvement and the need for care to vary over time can be challenging for all the caring teams. Conventionally palliative care services have become involved in the person's care and remained an integral part of the care pathway until death (Fig. 2.1). In the past, this may have been after a clear decision from "curative" to "palliative" care, particularly for a cancer patient – model 1. However, this has not been a sustainable system as many patients receive palliative chemotherapy even during the later stages of life, aiming at improving quality of life rather than extending life. This same pattern would apply for other advancing illnesses, and a pathway of integrated care is often seen – with reducing curative/active treatment as palliative care increases – model 2 [5].

Neurological diseases, with varying prognosis and varying needs, may require a new model of care – model 3 – in which palliative care/end of life care services have an episodic involvement with less contact between these phases of care [5, 6]. For instance a person with MND may need greater involvement at the time of diagnosis – coping with the shock of the diagnosis; and thereafter at points of transition, such as at the time of consideration of wheelchair or other aid for living; at the time of consideration of gastrostomy; when ventilatory support, by noninvasive ventilation or invasive ventilation with a tracheostomy, is being considered; at the end of life over the final weeks/days of life.

These models are shown in Fig. 2.1. Model 3, with episodic involvement, may be more appropriate for neurological disease as the needs vary over time. However, there is also increasing awareness that the same model of care may be appropriate for people with advancing cancer, heart disease, or respiratory disease as there is increasing active/disease modifying care and only specific phases, which may be seen as triggers, for palliative care involvement.

The variability can be very difficult for all involved in the care of a person with neurological disease. For some people, there may be a long disease progression with great variability in the functional and mental ability of the person – such as with MS – and the sudden deterioration, perhaps with an infection that does not on this occasion respond to treatment, may be a shock to all concerned.

The experience of palliative care in dealing with difficult discussions about the diagnosis or management and treatment options and advance planning means that they have a potentially valuable role from both relatively early in the process and then at later as the disease progresses.

## **Specific Issues, Autonomy, and Complexity**

### ***Mixture of Cognitive and Physical Disability***

Many people with neurological disease face altered autonomy which may be due to – changes in mood, cognitive abilities, communication, due to dysphasia or dysarthria, or more complex neuropsychiatric problems, such as:

- Dementia in MS
- Frontal lobe dysfunction or frontotemporal dementia (FTD) in MND
- Dementia in Parkinson's disease (Lewy body dementia)
- Severe cognitive change in Huntington's disease
- Hallucinations and psychiatric changes in PSP or Parkinson's disease
- Impulsivity or loss of judgment in dementia or PD
- Behavioral changes – in dementia, PSP, MS, MSA, and PD and FTD in MND

There is the potential of these changes to affect how end of life care is planned, and they can cause distress to patients, families, and professional carers, as the person may be very different to their previous personality or behaviour.

It may be necessary for people to discuss their wishes earlier in the disease progression, while they have the capacity to do so. Delaying until later in the disease may not be feasible, as they may then be unable to express their views clearly – due to communication or cognitive issues. However, this earlier discussion may be difficult for all concerned – patient, family, and professionals – help may be needed to allow the discussion and expression of the views to be made – and advance care planning arranged – see Chap. 7.

## ***Complex Treatments***

Some patients may receive complex interventions. These may include medication to treat the disease such as Parkinson's disease therapy, cytotoxics, and monoclonal antibodies in MS or symptomatic therapies. They often also include more invasive therapies treatments such as deep brain stimulation in Parkinson's disease or ventilator support in MND, either as noninvasive ventilation or more rarely invasive ventilation with a tracheostomy. These interventions often lead to complex ethical issues [7]. There may be disease progression and treatment may no longer be appropriate or acceptable to the person, and withdrawal of treatment may be discussed. The wider multidisciplinary team will face challenges in helping patients and their families in these difficult decisions and in supporting each other during these discussions. There is a challenge of working with/integrating the various teams and dealing with patients' expectations to decide when these complex therapies no longer extend life or improve quality of life, and when care needs to be predominantly palliative, i.e., "knowing when to stop."

## **Disease-Specific Problems**

### ***Parkinson's Disease (PD) and Other Parkinsonian Syndromes***

PD is a progressive condition, but with modern dopamine replacement therapy, symptoms can be controlled for several years, and life expectancy for people with PD can approach normal. However, most patients will suffer a progressive decline prior to end of life due to motor fluctuations, excessive dyskinesias, nonmotor complications including neuropsychiatric problems, both mood, hallucinations, and cognition, as well as autonomic dysfunction.

More complex treatments are possible and may be considered:

- Different means of receiving drug – apomorphine infusion/duodenal dopamine.
- Deep brain stimulation.
- Stem cell transplantation – this is still an area of research and its value is undetermined.

While there are a number of treatment modalities to consider in this situation, palliative care should be involved as the disease progresses and conventional therapies fail to help with symptom management. Patients should be encouraged to undertake advance care planning but they, their carers, and clinicians need to be aware that patients can deteriorate dramatically and may appear close to death due to treatment problems, and/or intercurrent infections, only to recover swiftly with appropriate treatment and resume their previous way of life. A Parkinson's disease specialist should be able to advise on optimal and appropriate treatment and what can be achieved in these circumstances.



Initially, it may be difficult to distinguish Parkinson's disease from other Parkinsonian syndromes, multiple system atrophy, and progressive supranuclear palsy. In MSA, there is a combination of Parkinsonism with pyramidal, cerebellar, and autonomic dysfunction. Similarly, PSP combines Parkinsonism with other features including limitation of eye movements, gait instability, cognitive loss, and autonomic failure resulting often in tendency to fall. The prognosis of these conditions is considerably worse (approximately 5 years from diagnosis), and almost all patients develop considerable disability requiring complex care, including palliative care.

### ***Multiple Sclerosis (MS)***

In the majority of people with MS (80 %), the disease initially has a relapsing course with attacks affecting different parts of the central nervous system, particularly the optic nerves, brain, and spinal cord. Initially, there is complete or partial recovery between attacks, but after 10 years or so, approximately half will eventually decline, a condition termed secondary progression. About 20 % will have primary progression from the onset. In the relapsing phase of the disease, disease-modifying therapies may be used to reduce relapses and therefore the risk of permanent disability. These therapies are thought to be ineffective in the progressive phases of the disease, and a proportion of patients will develop profound disability.

In most patients, the effects on longevity are limited; in some, the disease can result in severe relapses, rapid progression, and early disability. Patients can develop complex problems with pain; mobility problems and spasticity; fatigue; skin, bowel, and bladder care difficulties; communication and swallowing problems; and psychiatric and cognitive complications. Death related to MS is usually due to respiratory complications from dependency or other complications of immobility. In contrast to cancer, many patients will live for years with severe disability, and the stage when palliative care involvement may be required may well be protracted and the duration difficult to predict.

### ***Motor Neurone Disease (MND)***

While for many people with MND, the course is predictable and palliative care can be planned in a similar way to the paradigm for cancer patients, other patients can die suddenly from respiratory collapse without specific warning, and a small group (about 10 %) have a slowly progressive form of MND which can last 10–20 years.

Increasingly new treatments are used in the care of people with MND, in particular:

- Riluzole – a medication that has been shown to reduce the rate of decline of the disease progression but does not alter the disease itself. Often patients wish to

continue with the medication even after there has been profound progression and its use may no longer be appropriate

- A gastrostomy tube for feeding when there is severe dysphagia – either a percutaneous endoscopic gastrostomy (PEG) or a percutaneous radiological gastrostomy (PRG) may be inserted. This will allow nutrition and medication to be continued when swallowing is difficult and improves quality of life. However, as the patient approaches end of life, the use of nutrition and hydration through the gastrostomy may become less appropriate. Careful discussion about the reduction or withdrawal of fluids may be necessary.
- Noninvasive ventilation (NIV) is increasingly used to relieve the symptoms of respiratory muscle weakness, leading to respiratory failure. However, the disease will still progress, with increasing disability and problems, and the patient may become more dependent, and on occasions totally dependent on ventilatory support. Discussion about withdrawal of the ventilator may be necessary.
- On occasions, patients with MND may present acutely with respiratory failure and an uncertain diagnosis, and a tracheostomy with invasive ventilation is commenced. The patient can be maintained for long periods of time, with increasing disease progression and disability and with the risk of becoming totally locked in – with no communication. Discussion of withdrawal of ventilation may be necessary, and forward advance care planning will allow the person control of their care, even if they have lost capacity to communicate – see Chap. 7.

## *Other Conditions*

Other conditions including those of the peripheral nervous system can each pose their specific challenges, e.g., muscular dystrophy and progressive neuropathies. In many, the onset is at a younger age, and cognition is preserved, making these a particularly challenging and rewarding group of patients to care for. The nervous system is affected by malignancies in three ways. This includes primary brain tumors, metastatic tumors to the brain, and paraneoplastic conditions where the nervous system is affected by the body's immune response to an underlying malignancy. Again consideration needs to be given to the specialist management, involvement of a multidisciplinary team, and close liaison with palliative care when required.

Some of the clinical issues for each disease group are shown in Table 2.2.

The pathway shown below (Fig. 2.2) suggests that all patients should be regularly assessed for the various triggers that may suggest that there is a significant deterioration in their condition and that end of life issues need to be considered. From the initial diagnosis of a life-limiting condition, it is important that the changes in disease progression are recognized in all care settings as triggers for the introduction and subsequent stepping up and stepping down of palliative care input, based on holistic assessment which includes the needs of careers, joined-up planning, good communication, and regular review.

**Table 2.2** Common issues/triggers for progressive neurological diseases

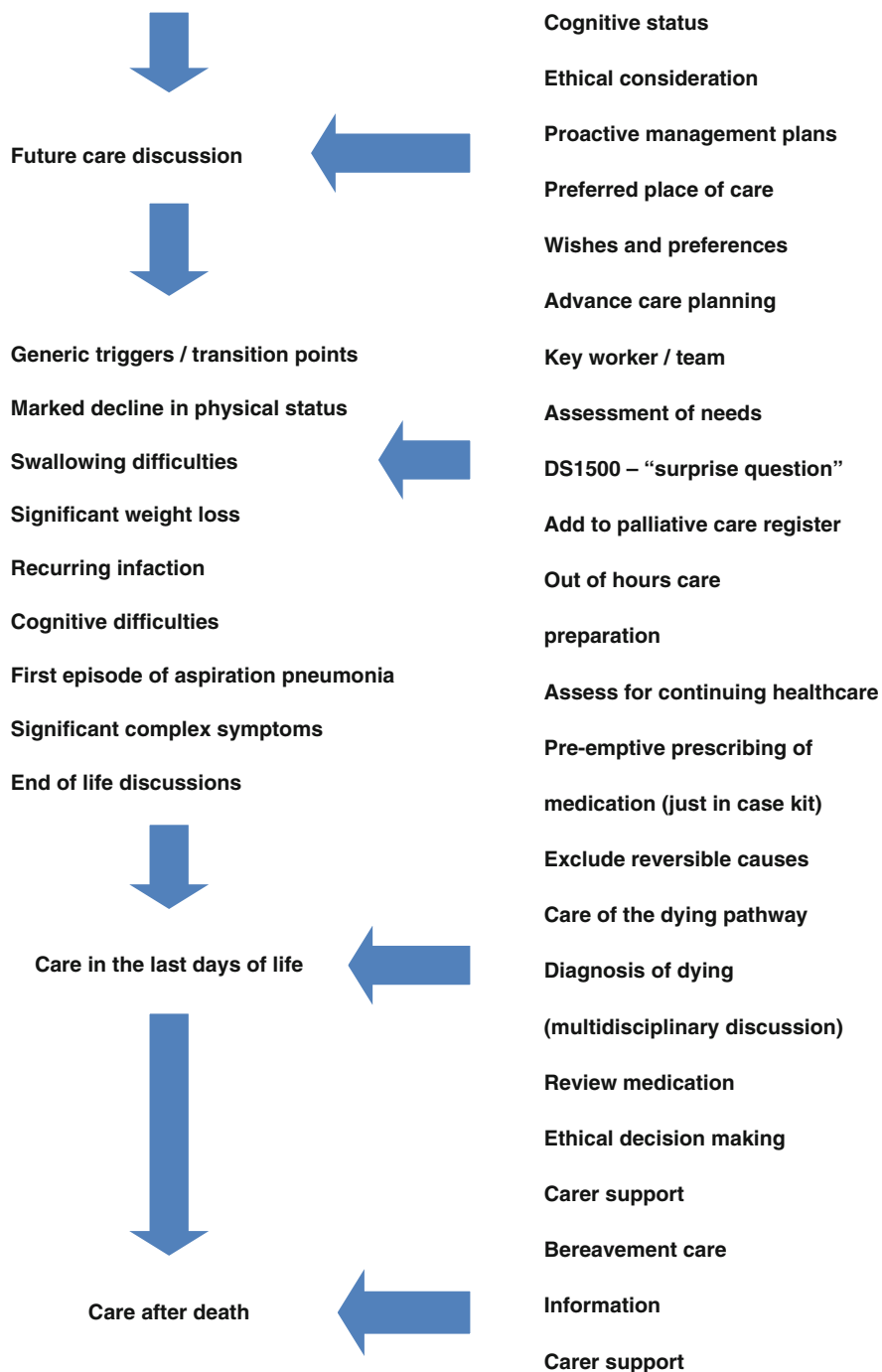
| Condition                      | Specific issues  |
|--------------------------------|--|
| Multiple sclerosis             | Depression   |
|                                | Spasms   |
|                                | Cognitive change   |
|                                | Dysphagia with reduced hydration and nutrition                 |
|                                | Skin fragility and increased risk of pressure sores            |
|                                | Mobility problems  |
| Parkinson's disease            | Rigidity   |
|                                | Pain   |
|                                | Agitation/confusion from sepsis                                |
|                                | Neuropsychiatric decline                                       |
| Motor neurone disease          | Respiratory failure or increased breathlessness                |
|                                | Reduced mobility   |
|                                | Dysphagia  |
| Multiple system atrophy        | Aspiration pneumonia   |
|                                | Depression   |
|                                | Hallucinations/anxiety/psychosis from neuropsychiatric decline |
| Progressive supranuclear palsy | Depression   |
|                                | Cognitive and behavioral change                                |
|                                | Visual impairment  |
|                                | Reduced mobility   |
|                                | Spasms   |
|                                | Dysphagia  |

## Recognition of End-of-Life Care

Identifying when someone with advanced neurological condition may be approaching the end of life care phase of their illness is important because it enables the appropriate care to be planned. It is important in those people who have lived with chronic disability to distinguish this from deterioration, due to an intercurrent illness.

However, there are often occasions when the triggers which could suggest that end of life should be considered are not recognized or even ignored. These include:

- The patient may not wish to discuss these issues or may have cognitive changes (which may or may not be recognized) that make the discussion more difficult.
- The family and close carers may not wish to face the reality of the deterioration and affect the opportunities to discuss these issues.
- The health and social care professionals may not be experienced enough or willing to recognize the triggers or changes they see – due to their close involvement with the patients and family, or their own personal views.
- The health and social care professionals may be reluctant to discuss these issues.
- The transition to end of life care may be so gradual and insidious that it is not recognized by the person or their carers.

**Diagnosis of neurological condition**

**Fig. 2.2** End-of-life care pathway for neurological disease (Adapted from National End of Life Care Programme [9])

There is the need for all involved to consider the issues, and there may need to be further developments within society to facilitate the openness to facing deterioration and death. *Dying Matters* [8] aims to encourage these discussions more widely in society and hopefully will open up these areas for wider discussion for all involved. This will also include greater awareness of the need to consider and discuss end of life issues by all the professionals involved. Although some team members may feel able to discuss these issues, others may not, and there may be a need to encourage greater discussion and openness with all the health and social care professionals involved.

The attitudes of professionals may vary greatly – due to education, personal experience, cultural or religious attitudes and experience. Greater awareness and discussion may require some professionals to alter their own attitudes and be aware of the particular needs and wishes of their patients. Education and greater discussion within all teams may help encourage this openness and awareness of patient and family needs. Integration of palliative care into teams will help considerably.

The End of Life Care Pathway [3] – see Chap. 1 page x – suggests consideration of end of life care throughout the disease progression, and the UK National End of Life Care Programme “Improving end of life care in long term neurological conditions – a framework for implementation” suggests certain triggers when end of life issues should be considered (Fig. 2.2). There are generic triggers for all neurological diseases:

- Swallowing problems
- Recurrent infection – particularly respiratory infection that may be associated with aspiration
- Marked decline in physical status – generalized weakness and reduced mobility and activity
- First episode of aspiration pneumonia
- Cognitive difficulties – confusion or more subtle cognitive change
- Weight loss
- Significant complex symptoms:
  - Pain
  - Spasticity
  - Nausea
  - Psychosocial or spiritual issues

The recognition of these issues may alert professionals that there has been significant deterioration, necessitating a change in emphasis in management perhaps from a more investigative and active management approach to a palliative approach. Some symptoms may be reversible in some circumstances – such as with an intercurrent infection, period of depression, or inadequate medication – and in all cases, it is important to identify and treat any reversible problems.

There may be specific triggers for a particular disease but it is essential to consider every patient individually, as there will be great variation in the disease progression and needs between patients, even with the same disease. The specific triggers for the main progressive diseases are shown in Table 2.2 [9].

Recognition and further discussion among the team – patient (if possible), family and close carers, and the wider multidisciplinary team – may then allow the management plan to consider the possibility that this person may be deteriorating and coming to the end of life. In this way, the care provided can be more appropriate and advance care planning and preparation for the end of life may start – as described in later chapters.

## Conclusion

The care of people with neurological disease, particularly at the end of life, is complex and involves many different disciplines and teams. There is the need to recognize the needs of patients and their families throughout the disease progression and identify and recognize the triggers that may indicate that there is significant deterioration requiring a palliative approach to improve the quality of life as the end of life comes nearer.

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