



Parkinson's
Disease Society

Working together locally

Good Practice Notes for Staff in Local Authority Departments:
Housing and the Community

No more neglect

The case of Mr S, a 63-year-old resident with Parkinson's disease found dead in his warden-controlled sheltered flat, was distressing, tragic and above all unnecessary.

Like many older people, Mr S had an emergency intercom installed in his home, which could be activated to alert his local authority should he need assistance. However, care staff felt that Mr S was abusing the service and this essential piece of equipment was taken away from him.

When Mr S collapsed due to a blood clot in his lung, without his alarm at hand, he was unable to summon help and as a result died alone only to be found days later.

The coroner's report declared a verdict of "death by natural causes contributed to by neglect" – neglect that resulted through a terrible misunderstanding of Mr S' condition and needs.

The Parkinson's Disease Society believes that this sad loss of a life could have been easily avoided if the staff involved had been more aware of the symptoms and fluctuating nature of Parkinson's.

As the leading UK charity reaching out to all people affected by Parkinson's, we aim to provide support, advice and information to people with the condition, their carers, families and friends, and to health and social care professionals involved in management and care.

The Parkinson's Disease Society is committed to the development of models of good practice in service provision and campaigns for changes that will improve the lives of people both with and affected by Parkinson's.

We hope that in reading this workbook Local Authority staff will gain a clearer insight into the range of complex issues concerning Parkinson's, and in doing so help to avoid cases like that of Mr S happening again.

The PDS is here to support you. If you would like further information, including how to join the Society please do not hesitate to contact us.

Parkinson's Disease Society of the United Kingdom

Website: www.parkinsons.org.uk

General enquiries: 020 7931 8080

We have substituted 'Mr S' for the real name out of respect for his family.

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The aim of this workbook

It is important that anyone working with people with Parkinson's disease understands the impact of the disease and how this may affect their work.

The Parkinson's Disease Society has literature which covers all aspects of the impact of the disease and emphasises good practice in housing and care.

This outline is provided to offer staff with a brief insight into the problems. It is not a teaching programme. It is designed to provide Community staff with a short introduction to the key issues that people with Parkinson's may experience while living in the community.

The following publications are recommended:

A copy of *The Parkinson* (the Society's quarterly membership magazine)

Parkinson's and You

The Drug Treatment of Parkinson's

The PDS information sheets *Communication, Falls and Hallucinations*

You may also find the following useful:

A local branch contact

The PDS Education and Training Team

Whilst this document provides a great deal of information regarding the facts about, and the challenges arising from, Parkinson's it is important to recognise the value of staff training in the seminar/workshop setting. The PDS has an Education and Training Team that delivers a range of workshops and seminars around the country.

Facilitated, interactive training enhances the way in which staff will absorb and retain the key messages that are so important to the care of those with Parkinson's and the involvement of their families and carers.

The PDS offers a flexible and financially accessible training programme for any staff or volunteers working with or providing care for people with Parkinson's. Should you require more information please do not hesitate to contact the PDS who will be able to provide details of the Education and Training Manager for your region.

The impact of Parkinson's

What effect does Parkinson's have on housing and care?

- People may require more frequent assessments as their condition can fluctuate both during the day and from day to day.
- The assessments should therefore be varied in time over a period of days, not as one-off events.
- Adaptations should be provided quickly and, wherever possible, free of charge.
- SMART housing options should be considered.
- No one with Parkinson's should be labelled as difficult or manipulative because of their condition.
- Due to the nature of the disease and the side effects of treatment, there may be times when they need more support and make more demands than other clients.
- Risk assessments should take into account the varying nature of the disease and should meet the needs of people with Parkinson's focusing on the worst-case option.
- Everyone with Parkinson's has the right to support and to feel safe in their own environment.

What do we need to understand?

It is important to remember:

- Parkinson's is a progressive and fluctuating neurological condition.
- it affects all aspects of daily living, including walking, talking, swallowing, writing and sleeping.
- an estimated 120,000 people in the UK have Parkinson's.
- the main management is with medication.
- medication can cause severe side effects which can impact on care.
- the main symptoms are tremor, rigidity and slowness of movement.
- many people experience pain, balance problems, fatigue, bowel and bladder problems, and sleep disorders in addition to these main symptoms.
- the loss of facial expression and spontaneity of communication can be a cause of extreme misunderstanding.
- care should be stage appropriate rather than age specific.

Appropriate care to stage not age

Parkinson's is considered in stages, each has different management issues and priorities:

- diagnosis
- maintenance
- complex
- palliative

(Parkinson's Aware in Primary Care. 2003 Parkinson's Disease Society Primary Care Task Force, PDS London)

The key message is to consider the person and their stage of Parkinson's in light of their abilities and needs.

Parkinson's Aware in Primary Care also highlights drugs that should be avoided in the management of Parkinson's where possible. These include:

- Chlopromazine
- Fluphenazine
- Haloperidol
- Prochlorperazine
- Thioridazine
- Metoclopramide

Flexible care regimes, good practice indicators and client and staff vulnerability

A sound understanding of Parkinson's disease, the provision of key workers and consideration for the fluctuating nature of the condition are fundamental to the care of people with Parkinson's. Care systems that enable the individual to actively influence their care and be involved when they are able, but respect their needs when they are less able, are preferred.

The rigidity, slowness of movement and tremor make people with Parkinson's very vulnerable in any setting. They often require more assistance and handling, their lack of facial expression can often disguise their true emotions and may be misunderstood for a lack of understanding, apathy or bad mood. The tremor may be mistaken as inappropriate sexual behaviour.

People with Parkinson's may be labelled as difficult and demanding because of their fears about receiving their medications inappropriately. They may be experiencing side effects from their medications that cause them to become immobile for no apparent reason. This can be alarming and difficult for staff to understand, especially if they are not familiar with the condition.

It is of principal importance that medications are administered at the correct times for each individual and not at times which may fit with the timings of night staff visits or warden calls. Many people with Parkinson's experience fluctuations throughout the day and from day to day in their symptoms. It can be difficult for non-specialist staff to understand this.

Staff can also be in a vulnerable position. Other colleagues and residents may resent the amount of attention given to a resident with Parkinson's, or the resident with Parkinson's may resent staff members or consider them uncaring, especially if they are unfamiliar with Parkinson's.

The key message is to ensure that all staff members are adequately trained in understanding the condition. The Parkinson's Disease Society's North and South Education Teams will be able to offer advice on training. Please contact the PDS for further information.

Adapting the home to help people with Parkinson's

Adaptations can sometimes make life easier. These range from small adaptations, such as grab rails, to major building work, for example, making a home wheelchair friendly or installing a downstairs shower and toilet. The use of an emergency call button will make a huge difference to the quality of life of people with Parkinson's. Relatively simple things like intercom systems for door entry, reserved car bays and a refuse collection service that takes the bins from a refuse area close to the house or flat can also help.

The home setting should be assessed for correct adaptations and aids. Thought should be given to access. For example, is there a dropped kerb to accommodate entering and leaving the building? Are rails available for support? Is risk minimised in the bedroom, kitchen and bathroom with suitable fittings and aids?

Although the PDS does not offer a building and adaptations advice service, it strongly recommends seeking an expert opinion. The first person to contact is an occupational therapist. They will assess the situation and suggest solutions, which may include adaptations.

Care and Repair, an organisation which aims to improve the housing and living conditions of older and disabled people, has a useful guide called *In Good Repair* which gives information on repairs, adaptations, funding and finding a reliable builder or tradesman.

The Disabled Living Foundation and the Centre for Accessible Environments should also be able to advise on adaptations and design issues.

It is important that those continuing to live in the community feel safe, and particularly safe in their own home. The use of emergency call services is excellent but staff must be aware that people with Parkinson's may not always be able to talk to the intercom or shout for help.

It is also useful if a contacts list is available at the home entrance. This should contain the staff most often in contact with the client and in particular those staff who understand Parkinson's.

What do people with Parkinson's and their families want from a home or care setting?

- Housing adaptations that are appropriate and quickly accommodated
- Staff that understand the nature, management and impact of Parkinson's
- To be assigned a key worker with a solid understanding of the condition
- To be involved in the activity planning of their care setting or home
- Access to a Parkinson's Disease Nurse Specialist if there is one in their area
- Access to Allied Health professionals who understand Parkinson's
- To be involved in their own care
- To be afforded understanding, dignity and respect at all times

The PDS believes that people with Parkinson's should:

- have access to housing adaptations or care settings that are responsive to changing needs.
- have access to support services and financial advice (including a multi-disciplinary team, speech and language therapists, physiotherapists, occupational therapists and social workers).
- receive continuous care.
- have an opportunity to take part in managing their illness.

Engaging with service users

Communication challenges

People with Parkinson's find that their ability to communicate with other people is often limited by the effects of the condition on speech, writing, facial expression and body language. The loss of these communication skills can have a profound effect on the quality of life of the person with Parkinson's as well as that of their family. Communication difficulties can also create a misleading and incorrect impression of the person being difficult, deaf, intoxicated or unintelligent. Misunderstandings arise due to a lack of awareness of these difficulties and many people with Parkinson's feel very socially isolated as a consequence.

Speech

About half of all people with Parkinson's have associated speech problems at the onset of their condition. As Parkinson's progresses, so too do their communication difficulties. Often, but not always, the severity of their speech difficulties relates to the extent of their physical difficulties.

Speech can be:

- slurred
- monotonous with a lack of variation and expression in the voice
- hoarse and tremulous
- lacking or fading in volume
- disordered in rate and rhythm
- hesitant or difficult to start
- progressively faster
- unintelligible with very slow response

As a result of all these factors, people with Parkinson's may find that other people misunderstand them. Talking in a crowd, over noise or in daily communicative activities, such as using the phone, may be impossible. This can further isolate the person with Parkinson's. It can also be a cause of great concern for family, carers and staff members, as they fear leaving people with Parkinson's who cannot communicate well on their own.

Problems with speech may also convey the incorrect impression that the person is mentally ill, depressed, apathetic or unfriendly.

It is also recognised that people with Parkinson's have extreme difficulty with the following in a conversation:

- taking turns talking
- following a multiple topic conversation
- interjecting

As a result they often use minimal responses. This coupled with a lack of facial expression further heightens the incorrect perception of people with Parkinson's as lifeless, unable to understand conversations or disinterested.

Non-verbal communication

The main problems people with Parkinson's can experience with facial expression include:

- lack of spontaneity
- disguising of true emotions or intelligence
- impassive appearance because of difficulty with frowning and smiling
- difficulty in recognising their own features when looking in a mirror
- making inappropriate responses which can be misinterpreted

In addition, there can be a lack of body language and non-verbal cues, such as smiling or nodding, due to the typical symptoms of Parkinson's such as bradykinesia (slowness of movement), rigidity (stiffness), and tremor (shaking). The person may have an air of general stillness with a reduction of body and hand gestures. Head and neck movements may also be restricted. Initiating movement can be difficult and can become increasingly slow and clumsy.

Conversely, some people experience abnormal involuntary movements (dyskinesias) as a side effect of anti-Parkinsonian drug therapy. These jerky and thrashing movements may be frightening to an onlooker. For the person with Parkinson's, they are distressing, painful and tiring and can affect any part of the body including face and mouth. As a result, people with Parkinson's may be unable to control their movements sufficiently to speak and communicate.

Relying on the patience of a listener can be frustrating and even depressing. Communication often centres around needs, such as going to bed or the toilet or needing a drink and all social conversation can stop. The ability to express one's personality or sense of humour can be severely affected by the loss of verbal and non-verbal skills and can make the person with Parkinson's depressed.

Facially, people with Parkinson's may appear to have lost their frown or smile. Their eyes seem to be lost in a gaze. Often their posture is poor and as a result they are unable to make eye contact easily. This can cause staff to feel hostile towards them.

Communicating tips

The Parkinson's Disease Society encourages all staff to consider the following dos and don'ts when talking to a person with Parkinson's

DO:

- keep all sentences short and precise
- encourage new ways of saying the message
- give them time
- make time to talk with them and give them extra time to respond
- try vocal techniques, such as suggesting the person with Parkinson's imagines that they are speaking in a bigger room than they are in
- maintain eye contact (NB: In some ethnic minority communities this is not appropriate where avoiding eye contact is a mark of deference and respect)
- ask them to repeat it in another way
- give them the opportunity to talk and encourage them
- talk normally

- listen carefully
- use short sentences and stress key words
- make sure they can see and hear you
- have patience and don't interrupt
- face the person you are talking to (NB: In some communities, this may be inappropriate and people may prefer you to sit side-on when talking to them)

DON'T:

- force the person to speak or to see people they do not want to
- talk for them unless absolutely necessary
- repeat exactly what was said again and again
- interrupt when they are trying to speak
- insist that the person pronounces each word perfectly
- become irritated when the person cannot communicate
- encourage the person with Parkinson's all the time as it can be tiring for them
- isolate the person with Parkinson's
- pretend to understand if you have not
- finish the sentence for them
- walk away while they are talking
- speak above noise
- compete with the TV or radio
- shout
- ask complex questions.
- ask their carer to speak for them, unless they wish this to be the case

In some instances carers will have an agreed strategy where they do all the talking to assist the person they live with. This can be misinterpreted as interference. Always try to find out from the person with Parkinson's if this is an acceptable coping strategy for them.

Swallowing difficulties and tips

Many people with Parkinson's disease experience swallowing problems. This may be when eating, drinking or taking tablets. It is important that staff recognise this and refer the person to a speech and language therapist for an assessment. This may fall to voluntary staff. Good practice ensures that these volunteers, or part time support staff, receive guidance from Social Services or Housing Agencies.

People with Parkinson's are very prone to problems of aspiration (choking on food). It is important to encourage a safe environment if a swallowing problem exists and that people are given privacy and assurance, and never pressurised.

It is important that care setting staff:

- encourage good posture when eating or drinking
- ensure that, before swallowing, the person is encouraged to lower their chin towards their chest as this helps to reduce the likelihood of food/drink going the wrong way and entering the lungs
- never encourage people to swallow with their head tilted backwards
- encourage taking small mouthfuls

Very cold fluids can stimulate a swallow and can be useful before breakfast or with a meal. Drinks can be thickened if required but note that if it takes a long time to swallow/drink, the drink may become too thick to swallow.

Staff may find the following procedure useful for helping people who have difficulties with swallowing food or drink:

- take in a breath and hold it
- take a small mouthful of food or drink into the mouth, close lips and then swallow
- swallow again to make sure the mouth and throat are cleared of any remaining fluid or food
- breathe in again as normal
- repeat the process while eating or drinking

Some people find it helpful when drinking to keep the cup or glass refilled above halfway to avoid the need to tilt the head back too far. This can also be avoided by leaving the last few mouthfuls or so in the cup. People with Parkinson's should be encouraged to take plenty of time when having food and/or fluids. They should never be rushed.

Understanding Parkinson's disease

What is Parkinson's disease?

Parkinson's is a progressive and fluctuating neurological disorder. It can affect all activities of daily living, including talking, walking, swallowing and writing.

What is the cause?

The cause of Parkinson's is unknown. However, the condition occurs when cells in the part of the brain that controls movement are lost. These cells produce dopamine, a chemical messenger that enables people to perform smooth co-ordinated movements. It is not known why these cells die. Once about half the normal levels of dopamine have been lost, the symptoms of Parkinson's appear.

(Morrish PK 1997. Parkinson's disease is not a long-latency illness. Movement disorders; 12 (6)849-54)

What are the key signs and symptoms?

The three main symptoms are:

- tremor
- muscle stiffness
- slowness of movement

However, not everyone will experience all three. Parkinson's disease is a very individual condition. Each person will present with different symptoms that are managed according to the needs of the individual and impact upon their quality of life on a case-by-case basis. This important point can often be misunderstood.

Other symptoms may include:

- a lack of facial expression
- an altered posture
- tiredness
- difficulties with balance
- difficulties with speech and writing
- depression
- problems with swallowing
- cognitive problems

How many people have Parkinson's disease?

It is estimated that as many as 120,000 people in the UK have Parkinson's. That equates to one in 500 of the general population. This increases to one person in 100 over the age of 65 and one in 50 over the age of 80.

(Quinn N (editor), Parkinsonism, Balliere's Clinical Neurology, Balliere Tindall, 1997)

Worldwide, 4,000,000 people are estimated to have Parkinson's

(World Health Organisation)

Studies indicate that 10% of the population of people in care settings have Parkinson's disease. Many people live with complex and challenging needs in their own homes or within the community.

Approximately 10,000 people are diagnosed with Parkinson's each year in the UK.

(Clarke CE, Parkinson's Disease in Practice, The Royal Society of Medicine Press Ltd, 2002.)

Most people are diagnosed over the age of 60, but younger people can also develop Parkinson's. It is estimated that one in 20 people with Parkinson's is under the age of 40 when first diagnosed. One in seven is estimated to be under the age of 50 when first diagnosed.

(Quinn N (editor), Parkinsonism, Balliere's Clinical Neurology, Balliere Tindall, 1997)

Who has Parkinson's disease?

Parkinson's does not discriminate. It can affect adults of either sex, of any race or age group. Anyone can develop the condition.

How is Parkinson's diagnosed?

There is no test for Parkinson's disease. It is a clinical diagnosis made on the observation of at least two of the three cardinal (main) symptoms being present. The objective tests carried out when people attend clinics are to eliminate other possible reasons for their symptoms.

Is Parkinson's hereditary?

Parkinson's is not hereditary in the majority of cases, but there are some very rare families where a clear genetic link can be found. However, this applies to less than one percent of people with the condition. It is highly uncommon for more than one person in a family to have Parkinson's and, therefore, development is usually sporadic.

Many researchers think that although Parkinson's is not directly inherited, some people may inherit a genetic susceptibility to developing Parkinson's if they encounter an environmental 'trigger'. Certain toxins or viruses may increase the likelihood of the onset of Parkinson's. However, further research is needed to identify precisely these "triggers" and to improve our understanding of genetic susceptibility.

How is Parkinson's treated?

Drugs are the main treatment for Parkinson's. They work to restore the level of dopamine in the brain, to enable the brain to make the maximum use of depleted dopamine or to improve symptom management. The most commonly used drugs are levodopa and dopamine agonists. Over time, people need to have their drug treatment reviewed as their needs change.

It is important that anyone diagnosed with Parkinson's receives regular reviews of their medication and how it is managed. This ensures that the correct medication is prescribed and that timing and dosages are also correct. The effect upon daily living can be very damaging if these are not monitored properly.

Treatments are initially very effective but long-term use can cause severe side effects, including for some people hallucinations, fluctuations and dyskinesias (unwanted involuntary movements), which can interfere with the ability to perform everyday functions.

Surgical techniques are also used to treat Parkinson's in a relatively small number of cases. These can include deep brain stimulation (thalamic, pallidal and subthalamic stimulation) and lesioning (pallidotomy, thalamotomy and subthalamotomy).

Physical therapies such as physiotherapy, speech and language therapy and occupational therapy play an important role in the management of Parkinson's. Professionals involved in the care of Parkinson's include: general practitioners; consultant neurologists or geriatricians; Parkinson's Disease Nurse Specialists; hospital and practice nurses; physiotherapists; speech and language therapists; occupational therapists; dietitians; social workers; and PDS information and support workers.

Working with the Parkinson's Disease Society

What can the Parkinson's Disease Society offer?

The Parkinson's Disease Society aims to:

- help all people with Parkinson's, their carers and families by providing support, advice and information
- collect and disseminate information on Parkinson's
- encourage and provide funds for research into all aspects of Parkinson's and to disseminate the results of research widely
- provide education to health and social care professionals

The PDS is a registered charity with 30,000 members. It is the leading UK charity dedicated to helping all people affected by Parkinson's and is funded almost entirely by voluntary donations.

Its work includes:

- a freephone Helpline (0808 800 0303) open Monday-Friday, 9.30am-9pm, Saturday, 9.30am-5.30pm (except Bank Holidays) staffed by nurse specialists and advisors offering advice, support and a 'listening ear' to anyone affected by Parkinson's
- information on all aspects of Parkinson's and a wide range of information sheets, booklets, leaflets and DVDs for people with Parkinson's, their families and carers, as well as professionals working with Parkinson's
- a quarterly colour membership magazine called *The Parkinson* about living with the condition
- a website full of news, information and advice – www.parkinsons.org.uk
- more than 330 local branches and support groups throughout the UK. Run by volunteers, they offer mutual support, information, social activities and practical help at a local level
- Information and Support workers providing advice, information and support
- a national network of staff working with people affected by Parkinson's, branches, support groups and local organisations, furthering the aims of the PDS
- outreach services for black and minority ethnic communities provide culturally appropriate information, advice and support, including some bilingual support to people in Birmingham and Leicester who have or care for someone with Parkinson's
- research into the cause, cure and prevention of Parkinson's, and improvements in treatments, as well as research in social care
- support for the PDS Brain Tissue Research Centre, based at Imperial College London, which gathers tissue for its own research, as well as to share with other Parkinson's researchers internationally
- promoting the development of Parkinson's Disease Nurse Specialists
- special interest groups: Younger Parkinson's Network for younger people (of working age) and their families, and SPRING for those with a special interest in medical research
- Policy and Campaigns is responsible for organising and supporting a range of national and local campaigns throughout the UK to improve the quality of life for people with Parkinson's, their families and carers. We seek to influence policy throughout the UK to ensure the needs of all people with Parkinson's are met effectively.

References and useful addresses

References

(Morrish PK 1997, *Parkinson's Disease is not a Long-latency Illness*. Movement disorders; 12 (6)849-54)

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www.parkinsons.org.uk

(*Parkinson's Aware in primary care*. 2003 Parkinson's Disease Society Primary Care Task Force. PDS London)

Resources

The PDS has a range of information sheets covering topics including care, communication, swallowing, choices for care and going into hospital. These are available from the Advice section of our website – www.parkinsons.org.uk



Parkinson's
Disease Society

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