

Implementing NICE clinical guidelines on Parkinson’s disease

Beverly A Ryton and B Jane Liddle

ABSTRACT – Implementing national guidance such as that produced by the National Institute for Health and Clinical Excellence should be a priority for NHS trusts. The best way of managing successful implementation is through collaboration across the healthcare community. This helps to improve communication, ensures progress is being made and enables healthcare professionals to concentrate on the whole pathway of care, not just specific aspects of it. The Sheffield Parkinson’s Stakeholder Group has successfully engaged all who are involved with providing the service across the city and has also received national recognition for its approach to implementation.

KEY WORDS: action plan, clinical guidelines, National Institute for Health and Clinical Excellence, implementation, Parkinson’s disease

Introduction

Parkinson’s disease (PD) is a neuro-psychiatric disorder which impairs the quality of life for the patient and places a strain on carers. Yet much can be done to alleviate and control the symptoms of the disease. The National Institute for Health and Clinical Excellence (NICE) clinical guidelines provide a benchmark for organisations and healthcare communities to use in order to establish how local service provision can be improved. This helps to ensure that patients have access to the best possible specialists and expertise in managing this condition. There is a requirement for NHS trusts to implement national guidance and although lots of progress has been made with developing services locally, the NICE guidelines have acted as a focus and provided impetus for the Sheffield Parkinson’s Stakeholder Group to drive the service forward. The group has taken a strategic overview of what needs to be done to improve current service provision.

Context

Parkinson’s disease is one of the most disabling illnesses of later life. It is a chronic progressive neurological condition and is associated with autonomic dysfunction, depression and cognitive impairment. It is estimated to affect about 160 per 100,000 population and prevalence increases with age.¹

The Parkinson’s Disease Society (PDS) has been in existence since 1969 and now provides a wealth of information relating to the disease, signposts help that is available and provides regular

updates on research projects that are underway or have been completed.² The PDS has been an advocate for promoting the expectation that patients suffering from PD should have access to specific drugs and interventions as the disease progresses. However the PDS has not been in a position to be able to drive national standards, produce comprehensive national guidance or to ensure it could be implemented. Therefore, prior to the publication of the NICE clinical guidelines in June 2006 no other definitive national guidance existed for managing the condition in such detail.³ The NICE guidance, however, should not be managed in isolation. Ideally it should be considered within a wider context of healthcare provision, alongside other national guidance, initiatives and requirements. The National Service Framework (NSF) for Older People sets standards that patients can expect from healthcare services and covers a broad range of issues.⁴ This document can be aligned to the care of patients with PD as the issues covered in the document apply to all older patients in hospital care. However the NSF for Long Term (Neurological) Conditions contains more focused quality requirements specifically in relation to PD and links closely with the NICE guidance.⁵ The essence of both clearly relate to the provision of quality services.

Both the NICE guidelines and the NSFs form part of the standards set out in *National standards, local action*.⁶ The NHS will be expected to demonstrate progress in planning and developing the levels of service specified in these national documents, working towards implementation over a period of time. It is therefore imperative that organisations begin to look at what needs to be done in order to achieve this and then map this against local commissioning and planning frameworks. Progress against the national standards will be assessed by the Care Quality Commission through statements of compliance for the annual performance assessments and potentially through more detailed service reviews.

NICE clinical guidelines

The NICE clinical guidelines provide recommendations for good practice that are based on the best available evidence of clinical and cost effectiveness. This guideline brings much needed clarity for managing this disorder and, importantly, both the PDS and Sheffield Teaching Hospitals NHS Foundation Trust were involved as stakeholder organisations during the development process.

NICE advocate a multidisciplinary approach which is necessary to help improve quality of life both for patients and carers. The guideline itself is comprehensive (83 recommendations) and covers a broad spectrum of clinical and non-clinical management

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issues, including communication, referral, diagnosis, neuro-protection, pharmacological therapy, surgery, non-motor complications, specialist input and palliative care. This clearly reflects the importance of total pathways of care as a main focus and driver for the NHS.

In order to assist with implementation, NICE have now developed a wide range of tools that can be used by organisations to discuss, plan and monitor implementation. The quick reference guide and slide set have been of particular help, however, local discussion prompted a more in-depth look at the recommendations contained within the guideline in order to establish priorities for Sheffield.^{7,8}

Parkinson's Stakeholder Group

In Sheffield, there is a strong and unified understanding that NICE guidance cannot be implemented as a stand-alone initiative. The only way to ensure guidance is implemented consistently is to work in collaboration with all partner organisations. Lots of work has been undertaken to promote this philosophy and the service is listed on the PDS website under 'good practice'.⁹

The Sheffield Parkinson's Stakeholder Group was established in 2004 and has cross-city representation from a number of specialists, service areas and the PDS (see Table 1 for a full listing of members by designation). The group meet on a regular basis, once every eight weeks, and it continues to be very well attended. Discussions focus on a wide range of issues pertinent to PD patients and the services currently being provided. The group has provided an extension of the multidisciplinary team-based approach for PD sufferers, with geriatricians working closely with neurologists to provide an integrated service across the wider healthcare community.

Within Sheffield, the four previous primary care trusts (PCTs) underwent local restructuring and reorganisation and as a

Table 1. Parkinson's Disease Stakeholder Group membership by designation.

Consultant geriatricians
Consultant neurologists
Consultant neurosurgeon
Consultant in old age psychiatry
Parkinson's disease nurse specialists
Parkinson's Disease Society regional manager
General practitioner with a special interest in Parkinson's disease
Physiotherapist
Occupational therapist
Speech and language therapist
Clinical effectiveness facilitator
Matron in medicine
Day hospital nurse manager
Partnership for older people projects representative
Pharmacist
Social work representative

result, Sheffield PCT was created in October 2006. This could potentially have led to delays and affected both enthusiasm and membership of the stakeholder group, but this has not been the case. Instead this has been seen as a great opportunity and one that the group has used to its advantage, both to strengthen links into newly formed strategic groups and to plan new service developments.

The benefits of having the stakeholder group continue to be realised, but already it has improved communication across services, helped to secure funding for specialist posts, facilitated the development of shared care protocols and clarified further actions and recommendations in order to continue developing the local service.

The group has received national recognition for its commitment to improving services and has been nominated for prestigious awards, winning the Hospital Doctor Award in 2006. The PDS has also visited the group to learn more about its work and are involving Sheffield in the 'Get it on time' campaign as a beacon site.

Local implementation trackers and action planning

It was agreed that establishing the current position would be the best starting point. This would enable the group to clearly highlight discrepancies and also to identify further recommendations and actions.

The local implementation tracker was devised and includes three key sections; the NICE recommendations, the current position and the Sheffield recommendations. These sections have been aligned to the key recommendations contained within the guideline. The group has collectively taken time to discuss, reflect upon and come to a consensus on what the priorities for local implementation are. This work and effort has resulted in a full and detailed document which clearly identifies the current position and what still needs to be achieved locally. The former has been established through combining a number of data and information sources, for example clinical audits, prescribing information, training packages, specialist input, observations and suggestions. Some examples are provided in Table 2.

The recommendations have been used to develop an action plan which the group will continue to use to progress specific actions. Each action is aligned to named contacts, timescales have been included as a marker and the status is also recorded indicating, for example, whether the action is in progress or has been completed. This will enable the group to monitor and develop implementation over a period of time, in keeping with national requirements.

Implementation successes

Communication

The local assessment tool is under review and discussions are taking place to agree the detail of what can realistically be done. Patient information is now readily available and information sessions are held regularly with patients.

Table 2. Examples from the local implementation tracker.

NICE recommendation	Current position	Sheffield recommendations
Communication Empowerment to participate and provision of information	Patient education groups Venue to be addressed, transport is a problem and attendance has suffered Specific questions on driving on assessment tool for nurse-led services but not recorded in patient notes A series of four-week Parkinson's communication groups have been run by one of the day hospitals by the SLT service to function as awareness raising, information giving and support for people with PD. Information sessions also run by OT	To re-advertise patient education groups to increase numbers. Give out leaflets to patients to actively advertise Compare local assessment tool against NICE recommendations (this includes information about driving etc) SLT have found these short-term information groups to be of benefit to clients and plan to retain them as part of the service offered to clients at ARC
Diagnosis Quick referral to specialist for diagnosis Use of SPECT	Audit of PD referrals (based on NICE guideline) July 2006 DAT scans are available but cost is a major factor	A rapid access clinic system could be used for patients for two week appointments. Service manager to begin discussions and this will also be put on the agenda for discussion at older people's group Consultants to bring some research evidence to one of the meetings to discuss in more detail A protocol to be drawn up on use of DAT scans which defines the circumstances when scans are advisable
Pharmacological therapy Drug administration	Clinical audits of drug prescribing and administration at both acute sites (2004) and prescribing across Sheffield (2007) Patients should be encouraged to bring PD medication into hospital with them	Group agreed to identify actions from the clinical audits and ensure they are taken forward Education and awareness raising on medication is required
Non-motor complications Depression Psychotic symptoms Falls	Day hospital: Depression – Hospital and Anxiety Depression Scale routinely used. Discussions with the psychologist first before direct referral made Psychotic symptoms – All PD patients seen by the consultant with a special interest. Treatment reviewed and documented in the patients collaborative notes PDNS: Depression – Geriatric Depression Scale used in patients with a low mood. This is documented in PDNS notes, and letters to GP and consultant. If problems continue referral made to psychiatrist Psychotic symptoms – Gradually withdrawing anti-Parkinsonian medication is considered. Well-tolerated mild symptoms are discussed with patients to agree what needs to be done Falls –The group collectively feel that falls are being dealt with appropriately across the city due to the falls clinics and joint working between the two day hospitals and the GPs/community teams	
Other key interventions PDNS Speech and language therapy	PDNS in post but position not substantive. Data collection required for impending review Patient satisfaction survey planned – (with PCT and clinical audit patient panel member) in order to confirm that NICE guidance is being met The guidelines make specific reference to the LSVT speech and voice programme. Funding required for training. Sheffield SLTs use the principles of the programme in their approach to therapy. Further discussion required	PDNS to collect data on length of stay and how patients benefit from nurse input both in hospital and the community. These data will provide evidence for the review in order to support efforts to make the post substantive Funding needs to be sought in order to ensure SLTs are able to attend the LSVT programme
Palliative care	Only patients who require symptom control are seen at present and there is no respite or day service available	Issue of palliative care and palliative respite for PD to be pursued via NSF board consultant geriatrician to contribute to the Sheffield review of palliative care services on behalf of the PD group

ARC = Assessment and Rehabilitation Centre (Day Rehabilitation Units); DAT = dopamine transporter; GP = general practitioner; LSVT = Lee Silverman voice treatment; NICE = National Institute for Health and Clinical Excellence; NSF = National Service Framework; OT = occupational therapy; PCT = primary care trust; PD = Parkinson's disease; PDNS = Parkinson's disease nurse specialist; SLT = speech and language therapy; SPECT = single photon emission computed tomography.

Diagnosis

Rapid access clinic slots are now available which ensure quick referral for diagnosis by a specialist. Ideally a dedicated clinic facility is required in order to minimise waits and negotiation continues to try to secure this in the future. The process for requesting dopamine transporter (DAT) scans has been agreed with medical physics and arrangements are now in place to request appropriate examinations.

Pharmacological therapy

As a result of the audit, pharmacists now provide education sessions for staff members on all wards regarding the importance of medication timing and administration. Patients are reminded by the ambulance services to bring their medication with them into hospital and the 'Message in a bottle' scheme is now being used.

All medication is now stocked on site and there is a 24-hour on-call service available to ensure that it is readily available. A self medication policy is now in place. The PDS has visited the hospital to find out more about the work undertaken regarding medication in relation to the 'Get it on time' campaign.

Non-motor complications

Feedback indicated that processes already existed in terms of assessment, referral and review for PD patients, however, a representative from old age psychiatry is now a member of the Parkinson's Stakeholder Group and this has enabled open discussion to continue to ensure links with the psychiatry service.

Other key interventions

As a result of the review the Parkinson's disease nurse specialist (PDNS) post was made substantive in August 2007. The PDNS is now linking with Partnership for Older People Projects to provide training to staff in care homes. Funding has now been secured to send speech and language therapists on training for use of speech therapy programmes eg Lee Silverman voice treatment.

Palliative care

The Liverpool end-of-life care pathway is now being used and is currently being audited. The consultant geriatrician remains involved in the review of palliative care services particularly in relation to PD patients.

Next steps

Discussions are underway to introduce the implementation tool and action plan into other areas in order to ensure regional consistency. It is also planned to utilise a similar approach for the NSFs, but this is at a very early stage of discussion.

As discussions continue with the new PCT, and processes become more formalised, the group may need to categorise specific actions in order to distinguish between what may be rela-

tively easy to complete and what may prove to be more challenging. For example to establish what could be achieved locally with little or no extra resource, what might fall under the remit of education or communication, and what would need to be highlighted via the financial processes as funding or extra resource will be required to address the issues.

The British Geriatric Society's Movement Disorders Section aims to facilitate a national audit of the NICE guidance for PD. The Sheffield local implementation tracker is accessible on the website to help take the work further.¹⁰

Conclusion

The NHS currently faces many challenges, not least effectively managing the healthcare of our increasingly ageing population. The focus of numerous government initiatives remains on older people and it is only by looking at the wider context of healthcare and the priorities faced by the NHS that services can be aligned in order to improve care for this patient group.

Collaborative working across the healthcare community, effective engagement and integration, and locally developed partnerships will all ultimately help with this task. Care needs to be viewed as a total pathway, one which the patient moves within and across in order to access the appropriate services. Services need to be integrated to avoid duplication and ensure finite resources are used in the most effective ways in order to provide services of the highest quality.

Collating the current position has been a time consuming but valuable process that could not have been completed without the entire group's input and feedback. It has been an iterative process yet one that has helped the group to identify all the excellent work that has been continuing across the healthcare community. However, the key to further achievement is remaining realistic yet optimistic and using every opportunity to work together more effectively. The implementation tool and action plan have proved to be successful in terms of gathering important information in order to establish what currently exists against national recommendations. Work continues locally in order to refine processes and to ensure information is accessible in paper and electronic formats.

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WORKING PARTY REPORTS

Palliative care services: meeting the needs of patients

There is increasing recognition that the principles of palliative care medicine can be implemented beneficially across most of the NHS and within most specialties. This report therefore reflects the shift in practice from predominantly cancer care to a much broader application. It includes recommendations on disseminating best practice both for those with terminal illness and for those with incurable illness earlier in the disease trajectory. Looking to the future, there is specific consideration of changing demographics, the importance of interdisciplinary care, the dissemination of care pathways, and new funding models.

Palliative care deals with an area of modern medicine that raises many ethical dilemmas, both in respect of treatment decisions and the formidable obstacles in undertaking research. For

although palliative care is generally considered a 'good thing', it should be subject to rigorous scrutiny and justification of both process and fundamental precepts.

This report is both philosophical and practical and will be relevant to all doctors and allied healthcare professionals who wish to ensure that the needs of patients and their carers are properly met. It is essential reading for healthcare planners, commissioners of palliative care services, and for providers of undergraduate and postgraduate education for all doctors. As end-of-life care may affect us all, this report deserves a wide readership and detailed consideration of its comprehensive recommendations.

Report of a Working Party

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