Telephone Advice Guidelines
for Nurses Working in Parkinson’s Disease
Introduction

This guidance has been developed by a team of Parkinson’s Disease (PD) experts, in conjunction with Healthy Alliance to give practical advice for nurses and other healthcare professionals who provide, or are developing, telephone advice services for people with PD.

The recommendations in this document should be supported by additional information, particularly the Royal College of Nursing (RCN) existing ‘Telephone advice lines for people with long term conditions’ (May 2006), guidance related to the nurse/practitioner’s specialist areas of practice and any local agreements that may be in place.

The content of the RCN existing ‘Telephone advice lines for people with long term conditions’ has been used as a guide and point of reference for the content of these guidelines. Healthy Alliance would like to thank the RCN for kindly providing permission to reference this document.

Foreword

The Parkinson’s Disease Society (PDS) welcomes the development of telephone guidelines which are specific to healthcare professionals working in PD.

Approximately 10,000 people in the UK are diagnosed with PD each year, and every individual needs to be confident that they will receive the expert advice and support they need as their condition progresses. The complexity of the condition means that there are a wide range of associated symptoms which are individual to each patient.

PD specialist services are vital for patients with this chronic condition but are often stretched, with the patient case loads continuing to increase, which means that face-to-face consultations can often be many months apart. Access to services such as telephone clinics can be an important form of interim support for patients in receiving reassuring advice and direction from a qualified healthcare professional.

The National Institute for Health and Clinical Excellence (NICE) guidelines in Parkinson’s disease (June 2006) advocate patient self-management and services such as this to assist patients in staying independent, whilst also giving them easy access to advice on dealing with any issues which arise, for improved confidence/empowerment and quality of life.

The White Paper ‘Our health, our care, our say: a new direction for community services’ (January 2006) identified key areas for change which included more personalised care driven by better access to information and services.

This guidance aims to assist nurses to implement these areas of policy in their clinics to improve standards of service for people with PD.

Steve Ford, Chief Executive Officer, Parkinson’s Disease Society
1. Why Introduce a Telephone Advice Service?

Telephone advice services provide a significant contribution to patient self-management, which is in keeping with the philosophy set out in the Government White Paper, ‘Our health, our care, our say’\textsuperscript{5}, and form an important addition to care, providing ongoing support and education.

The value of telephone support in the management of chronic diseases, such as PD, has been well recognised. However, this telephone contact can be difficult to manage from a time perspective and formalising this activity can help nurses to manage their time more effectively as well as setting important boundaries for patients in their care. By providing a dedicated telephone advice service, support can become more structured and streamlined. This service can also either enhance or facilitate record keeping and the auditing process.

Importantly, the Government is launching a new initiative under which healthcare professionals will prescribe information, as well as medications, to patients. People with long-term conditions or social care needs will receive ‘information prescriptions’ which will guide them to relevant information about their condition. A telephone advice service may offer support to patients who may have queries or concerns regarding any information they receive in a way that is controlled and professional for both nurse and patient.

2. Setting-Up a Service

When setting up a telephone service it is particularly important to manage the expectations of the users and to plan and manage the service correctly.

**Considerations for setting up a service:**

- **Plan your infrastructure** – spend time documenting your aims and objectives with your team to agree on a service which suits the setting, locality and structure of the team.
- **Consider your caseload** – identify the feasible amount of time in your week/day/month you are able to set aside for telephone advice services.
- **Check established protocols within your area** – ensure that you are working within the local guidelines set by your employer.
- **Cost considerations** – ensure that you are working within local cost guidelines/funding available and seek guidance from your local PCT.
- **For those Parkinson’s Disease Nurse Specialist’s (PDNS) working in the acute sector it is important to be aware of tariffs set this year, as all services provided will have a cost attached. Consider developing a robust business case to present to the commissioners to secure funding for the service.**
- **Ensure that working on the telephone is in your job description** – in order to ensure that your employers are aware that you are setting-up and administering a telephone service.
- **Mobile or office based telephone?** – mobile phones can allow for greater accessibility but can also be more difficult to manage. Consider using a landline telephone with a forwarding system to a mobile phone in case of emergencies (see Top Tip box on using answer phone services). It may also be appropriate to consider setting up another line which is accessible when your clinic is in progress.
- **Patient confidentiality** – identify a location that you will be able to conduct the calls in private to ensure the same level of confidentiality for patients you are consulting with over the phone, as those you would see in a clinic.
- **Technology** – review the current equipment in place for conducting the call, you might be able to request an update on your phone and voicemail in light of the introduction of the service.
Service Provision Scenarios

There are various scenarios where nurses might find themselves in consultation with a patient over the telephone. You may find that just one or a combination of all of these scenarios should be used to devise a framework that is suitable for your service:

Scenario 1: Telephone clinics with an appointment schedule

This is similar to the face-to-face service but is conducted over the telephone and features pre-scheduled appointments made in advance of the allocated time

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<th>Pros</th>
<th>Cons</th>
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<tr>
<td>• Structured way to provide advice to patients in a cost efficient manner&lt;br&gt;• Encourages self-management and ownership from the patient&lt;br&gt;• Can be easily cancelled/rescheduled in case of holidays/emergencies</td>
<td>• Does not allow for dealing with ad-hoc patient issues/requests&lt;br&gt;• Lack of flexibility provides no added value to service for patients&lt;br&gt;• Challenge in keeping to the allotted time frame to avoid patients calling and getting the engaged tone or answer machine</td>
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Scenario 2: Patient follow-up via telephone conducted by the nurse

Nurses set aside time each week to contact patients identified as requiring follow-up. The calls conducted are based on the nurses’ discretion; a review of patient records or following recent face-to-face appointments

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<td>• Allows nurses to select patients who require follow-up&lt;br&gt;• Ideal for patients who have just started on medication who may only need 5-10 mins of nurses time&lt;br&gt;• Avoids inconvenience to patients of returning to clinic and saves on clinic space and time</td>
<td>• Patients may not be available at time of the nurses’ call&lt;br&gt;• No time limit attached to call creates confusion and potential aggravation with patients&lt;br&gt;• Does not allow for incoming calls from patients with issues/requests</td>
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Scenario 3: Clinic ‘Hotlines’

Time-specific sessions for patients to call in regarding issues that have arisen since the last review or clinic appointment

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<td>• Effective use of time when running smoothly&lt;br&gt;• Encourages self-management and ownership from the patient</td>
<td>• Frustrations can occur when patients can’t get through&lt;br&gt;• More difficult to use time effectively&lt;br&gt;• Difficult for single worker services</td>
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Whichever combination of scenarios or type of service you provide it is essential to keep to this framework and communicate any changes that are made to all relevant parties in order to manage expectations effectively.

It is not advisable to take calls ‘as and when’ as this provides no structure. Patients should be encouraged to go through the clinic hotline or, if possible, reschedule the call to a designated time.

**Important patient access considerations:**

**Physical impairment** – for patients with hearing problems this type of consultation may not be appropriate (or they will need to be assisted by one of the ‘type talk’ services now available). Other PD-related problems such as speech difficulties will also impact on patient access and could impact their confidence when using such a service. This must be considered when offering this service.

**Language barriers** – consider translating the information about the service or facilitating a conference call consultation with an interpreter to improve access for patients who may have difficulties with English.

The Language Line or the National Interpretation Service can also be used for advice lines, doctors/GP practices and 999 services. By calling a freephone number a professional interpreter is available for a three way conference call and the service provider will help to identify the language needed. There are costs associated with these services, although considerably less than hiring a full-time interpreter.

For more information on telephone translation services, visit: www.languageline.co.uk or www.nisuk.co.uk (links tested September 07)

It may be appropriate to have a patient’s carer/relative present on a consultation with a non-English speaking patient on a three-way call, which is also more cost-effective option and may also be preferable for the patient.

**Cognitive impairment** – patients may have short term memory loss or difficulties in comprehending instructions. Ask the patient to repeat the advice which has been given or, if possible, ask to speak to the carer/relative to confirm the information/advice given.

**Defining your boundaries**

By mapping out your service you should be in a good position to understand what you can and cannot provide as part of the service.

It is important for nurses to remember that there may be more suitable avenues which the patient can take to address their concerns and that this should be communicated to the patients directly at the time.

Communicating the details of the service to patients from the outset will assist you in setting clear boundaries, which you must adhere to as much as possible.

**Training and competency**

It is important that you feel comfortable giving advice in a clinic-based setting before you initiate a telephone service. Nurses should have ideally attended the Healthy Alliance Nurse Induction Programme before setting up a telephone advice service.

Visit [www.parkinsons.org.uk/for_professionals.aspx](http://www.parkinsons.org.uk/for_professionals.aspx) (link tested September 07) to access ‘Competencies: an integrated career and competency framework for nurses working in PD management’ and the ‘National Service Framework for Long-term Neurological Conditions’ as well as a range of other professional resources to assist practitioners in PD.

Core skills in conducting telephone consultations are not just about clinical experience or extracting information from patients on sensitive issues but can also be about having the conviction to end calls.

There are various courses available for training people to communicate on the telephone.

Three basic courses include:

- **Level 1**: Foundation skills
- **Level 2**: Developing skills
- **Level 3**: Providing emotional support

However, there may also be local training sessions and support networks that you will be able to joint to assist you in honing your skills.

For more information, please visit: [www.helplines.org.uk](http://www.helplines.org.uk) (link tested September 07)
3. Maintaining a Service

Once you have established your service there are some core areas on which you should focus your attention to ensure your service runs smoothly, maintains a high standard and continues to provide benefits to patients and the clinic.

Recording information from calls

It is of vital importance that any information you are given by the patient during the call is managed with accuracy to ensure high standards of care.

There are various practices that you can introduce to ensure that the telephone clinic information is used effectively:

- Add notes of correspondence to manual notes using a pre-designed sheet which includes all of the information that needs to be recorded
- Develop a template to record information from the telephone answering system which can be transferred to the notes template before you return the call
- If using an electronic database, ask the service provider or IT team about ways to easily log information sourced on the telephone
- Copy important information, such as changes in medication, to the wider team to ensure that they are up to date on developments and can manage or advise accordingly
- When dealing with challenging patients or those with cognitive impairment, document the outcomes by sending a letter to them and their carer/relative to ensure that there is a written log of the conversation and the advice given
- When dealing with medication, worrying symptoms or other important aspects of a patient’s condition a letter should always be sent to the patient, carer/relative and GP. The patient should also be seen on a face-to-face basis as soon as possible

For access to examples of recording templates, please contact healthyalliance@gsk.com or visit the Parkinson’s Disease Nurse Specialist Association (PDNSA) website www.pdnsa.net or the PDS website www.parkinsons.org.uk. (links tested September 07)

Managing time effectively

It might be useful to set consultation periods to a certain time period. The nurse should then use the Step by Step Guide in this document to map out how long each step of the call might take and try to stick to this in order to manage call duration.

Communicating a maximum call duration in the patient information distributed, as well as at the outset of the call, will also assist the nurse in keeping within the designated timeframe and manage the caller’s expectations.

Returning calls

All standards which are set for conducting and returning calls must be realistic and achievable.

It may be useful to develop a protocol document which sets out the process for returning calls. This might stipulate the number of times the nurse calls back before there is no further action or action which is taken if a third party answers the call.

Handling inappropriate calls

Some patients with PD may call their nurse for a social chat and it is important to explain that this is not part of the service. Most patients accept that nurses are busy and communicating this can be a good way of concluding the call. For all nurses, this situation is an example of the delicate balance between providing a good service for their patients and using time appropriately to ensure optimum patient outcomes across the service.

Patients with cognitive impairment may also be unnecessarily abusive and difficult to manage via the telephone. You may also experience distressed calls from patients who are suffering from depression or anxiety.

For further advice and information please log onto the PDS website www.parkinsons.org.uk. (link tested September 07)
Support systems
It is important that you feel supported when conducting these calls on both a professional and emotional level. Dealing with issues which may arise should be referred to line managers. There should also be opportunities to debrief following calls, to ensure that you feel supported and to prevent any feelings of isolation which may be experienced. Utilise regional PDNS groups or local nurse specialist meetings as a means of support if these are provided in your area.

Administrative support
If you have access to administrative support, it may be possible to engage with them to assist you in filtering and triaging calls to other healthcare professionals, the content of which are outside of your remit. However, it is extremely important that non-medically qualified staff and those without experience in managing PD do not give out medical advice.

4. Improving the Service

It is important that the service is constantly reviewed in order to improve standards of care.

Getting feedback from patients
As well as the initial audit of patients it is worth conducting an annual evaluation of the service with your patients to gauge ways in which you can make improvements to better fit their needs.

Getting feedback from the wider team
Feedback should also be encouraged from the wider team, including GPs and multidisciplinary specialists. Requesting their involvement in the development will also ensure they are more involved and more inclined to provide assistance in resourcing the service.

Share your knowledge and experiences
Learning from other nurses and healthcare professionals about their experiences with telephone advice services and sharing this knowledge within regional groups can assist in aligning services across the local area.

Audit review
Following an audit it is useful to review and act on the results/data. This may alert you to discrepancies and will inevitably improve the overall service. It will also allow for continued benchmarking to monitor changes and improvements to the service.

5. Governance Issues

Please ensure you have read the RCN ‘Telephone advice lines for people with long term conditions’ in advance of setting up a service to ensure that all clinical governance issues have been considered.

IMPORTANT TO NOTE: Safety of advice
It is important to note that there should be clarity about the aims and objectives of the service, as well as the remit of the nurses/practitioners providing the support. In particular, nurses should be clear about their position regarding changes of treatment or dosages and supporting documentation.
A Step by Step Guide to Conducting a Telephone Consultation

What the telephone consultation should cover:

**Step One: Collect key information**
- Caller's name
- Date of birth
- Hospital/NHS number or address
- Telephone number
- Carer/relative information
- Permission to discuss information with carer/relative should a return call be required

**Note:** It may be useful to share any relevant information/documents with the patient in advance of the call to help them be prepared for the telephone consultation.

**Step Two: Information required before offering advice**
- Clarification of current treatment, monitoring or recent medical interventions/problems
- Confirmation of all prescribed medications including over the counter (OTC) and complementary therapies
- Any other medical or surgical treatments the caller is receiving from other specialists
- Check any allergies that patients may have to medication

**Step Three: Establish a clear outline of the issue**
- Clarify the problem and the steps taken by the patient to date to resolve the issue

**Step Four: Once the issue has been established**
- Gain clarity and agreement on the steps necessary to resolve the problem or seek further help
- Establish time frame for self-management strategies if advised, when to review the success of such strategies and who should review them
- Agree what the caller should do if problems continue
- Establish a mutually agreeable time to return a call if a follow-up is planned
- Agree who will instigate the review call
- Communicate the patient outcomes to other healthcare professionals or third parties to ensure consistency of care
- Document the outcome of any advice given and send to the patient and/or GP if appropriate
TOP TIP: Conduct a Pre-Service Audit

- Before you set up a service it might be useful to record the amount of time you are currently spending on the telephone with patients over a period of two to four weeks, noting when the calls are taking place and brief details on their content.
- **This will enable you to:**
  - Clearly define the amount of time spent on the telephone as evidence of the need to formalise the service
  - Review data from the audit to develop a tailored system which works to complement your existing practices
  - Demonstrate the need for this service to your managers to secure funding and additional resources
  - Ascertain what your patients would like from a telephone service
  - Be clear on what your service offers, and what it doesn’t, based on your existing experiences
- An audit will also provide you with a valuable benchmarking tool to evaluate the benefits of setting up or improving your service.
- For an example of an audit sheet, please contact healthyalliance@gsk.com or visit the PDNSA website www.pdnsa.net or the PDS website www.parkinsons.org.uk. (links tested September 07)

TOP TIP: Information Sheet for Patient

- Once you have designed your telephone advice service it is important to consider how you will communicate the service to the users.
- Developing an information sheet on the service not only allows you to manage users expectations but can offer a good opportunity to direct them to other services such as the PDS Help Line, patient advocacy groups or expert patient panels.
- The information sheet and contact details should also be passed to the PDS so that they can refer any patients with requests relating to the management of their condition.
- This document is also useful for explaining other important information, such as the means by which the outcome and next steps will be communicated to the patient.
- The information sheet can also be used as a point of reference when challenged by the patient or carer regarding the logistics of the service.
- For an example of a template information sheet for patients please contact healthyalliance@gsk.com, or visit the PDNSA website www.pdnsa.net or the PDS website www.parkinsons.org.uk. (links tested September 07)

TOP TIP: Using a Recorded Answerphone

- It is important that all nurses who regularly use the telephone have a recorded answerphone message which is updated on a regular basis.
- The recording should state the whereabouts of the nurse, the expected date that the message may be picked up and also provide alternative contact details or a course of action in case of an emergency.
- The recording should reiterate the need for the patient to leave their full name and contact details in order for the nurse to identify the correct patient to call.
- The message should also give a timeframe for returning the call (i.e. within 24, 48 or 72 hours). However, all of this information must be balanced with keeping the message concise.
- The answerphone should also be checked on a regular basis with all messages recorded and passed to a member of the team to be addressed accordingly.
The members of the Telephone Advice Guidelines for Nurses Working in Parkinson’s Disease group are:

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With thanks to:

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Healthy Alliance is a joint initiative between GlaxoSmithKline (GSK) and the PDS, to provide a dedicated package of support and training for Parkinson’s Disease Nurse Specialists, covering the UK.

For more information please contact healthyalliance@gsk.com

References:
1. Royal College of Nursing. Telephone Advice lines for people with long-term conditions – Guidance for nurse practitioners. May 2006
2. The role of the Nurse Specialist www.pdmsa.org (Link tested September 2007)
3. PDNSA, RCN and PDS. Competencies: an integrated career and competency framework for nurses working in Parkinson’s disease management. June 2005

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