



Royal College
of Nursing



Telephone advice lines for people with long term conditions

*Guidance for nursing
practitioners*



Royal College
of Nursing

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Guidance for nursing practitioners

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Foreword

Foreword from Beverly Malone

The telephone is an essential and effective means of communicating and sharing information in our society. In many health care settings now, telephone services are providing innovative approaches to delivering services and providing advice. For those people with a long term health problem, such services can be invaluable, because they provide expert advice when self-management strategies fail to achieve health benefits or control symptoms

This document supports practitioners who provide telephone advice. It outlines important steps in developing high quality, sustainable and cost-effective telephone services, working with the local community and patient organisations.

I warmly endorse this guidance, which provides a much needed framework for practitioners providing telephone support to individuals with long term conditions.

Beverly Malone RN PhD FAAN
General Secretary, Royal College of Nursing

Foreword from Bridgit Dimond

Communication has always been at the heart of patients' health care and telephone services are now developing this further. Health practitioners who are giving advice over the 'phone need to be aware of the pitfalls and the limitations of this form of communication. A nurse is accountable for care delivered by telephone, but if she ensures that standards are in place to provide the reasonable care which the patient requires, then she will also protect herself and her colleagues from complaints and potential litigation.

This guidance from the Royal College of Nursing (RCN) comes at an apposite time. It provides not only the advice needed to establish a telephone advice service for patients with long term conditions, but also guidance to ensure that the service follows best practice and is regularly monitored to maintain standards. Helpful appendices provide examples of log sheets, and information on patient organisations. Practitioners will welcome this document as a significant resource for the establishment and maintenance of high standards in a challenging area of health care.

Bridgit Dimond
Emeritus Professor, University of Glamorgan

Foreword from Carol Black

The Royal College of Physicians recognises the importance of supporting and working with patients and established a patient and carer network in 2003 to build upon the strong collaboration between patients and physicians to improve health care outcomes. I am therefore delighted to see that the working party who developed this guidance included patient-led organisations. This guidance document will be a valuable resource for practitioners who provide specialist telephone advice to individuals with long term conditions.

Professor Carol Black
President, Royal College of Physicians

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Executive summary

This guidance gives advice for practitioners who provide, or are developing, telephone advice services for people with long term health conditions.

Key recommendations include:

Principles of good practice

Before providing such a service, nurses should demonstrate:

- ◆ competencies in communication and consultation skills in routine clinical practice
- ◆ effective clinical decision-making skills
- ◆ awareness of governance issues that reflect safe practice and reduction of any potential risks related to telephone advice.

Setting up a service

Practitioners should:

- ◆ identify the needs of the community who will access the service including ethnic and minority groups
- ◆ scope local and national patient-led organisations that can provide complementary support for individuals with long term conditions
- ◆ prepare business proposals that include time management and financial planning for a sustainable service
- ◆ provide an explicit remit of services and identify clinical supporting services and the potential impact on specialist services
- ◆ provide appropriate documentation including patient information leaflets and audits
- ◆ effectively manage user and professional expectations.

Service provision

Nurses providing the service should:

- ◆ adhere to governance and legal issues
- ◆ keep clear documentation and records
- ◆ plan for the ongoing training and support needs of practitioners, including clerical support
- ◆ identify and manage difficult issues related to telephone advice line support
- ◆ provide regular reviews and evaluation of services, including audit and other appropriate outcome measures.

The recommendations in this document should be supported by additional information and guidance related to the practitioner's specialist areas of practice.

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Introduction

Telephone advice line services provide a valuable contribution to initiatives that focus on promoting patient empowerment and the use of self-management strategies for individuals (and their partners or carers) with long term conditions (LTCs). Such services form an important addition to care, providing ongoing support and education to individuals (ARC, 1997; Arthritis and Musculoskeletal Alliance, 2004).

The quality and equity of service provision may vary across the UK. However, to ensure safe practice and support practitioners in their developing roles, it is imperative that there are clearly documented frameworks. Guidance on the use of telephone advice lines have been published in the past (Telephone Helpline and Broadcast Support Services Guidance Group, 1993; RCN, 1999). The changes in practitioner roles and responsibilities and the increasing changes in health care provision now highlight the need for new guidance. There also remains a wide variation in practice between specialist fields, and a lack of national guidelines (McCabe et al., 2000).

The Royal College of Nursing Rheumatology Forum (RCNRF), along with members of the rheumatology patient and professional groups recognised the need to develop new guidance. A wide range of other fields of nursing practice and patient organisations were consulted to contribute to the development of this document. It gives advice for practitioners who provide or are developing telephone advice services to people with long term health conditions. To inform this guidance evidence was reviewed and graded (see Appendices 3 and 4). The working party also considered issues related to the training and competencies required as well health care outcomes and cost analyses.

The term 'helpline'

The term 'helpline' is well recognised by providers and users. However, the RCNRF working party strongly advocates referring to such telephone support as 'advice lines'. This is to highlight the strong emphasis on self-management principles when accessing telephone services, and therefore setting caller expectations in a more realistic context (Thwaites, 2004).

Aims of the document

The document aims to:

- ◆ provide a framework for practice, recognising that advice line support is a pivotal resource which should be adequately planned and managed
- ◆ identify and grade research undertaken in this area of practice, highlighting examples of best practice and opportunities to develop innovative approaches to supporting individuals with LTCs
- ◆ aid practitioners in their understanding of patient-led telephone advice lines and collaborative ways of working to enable the optimum care for the service users
- ◆ guide practitioners in planning a telephone advice line service
- ◆ ensure the advice line is sustainable over time, with appropriate infrastructure and succession planning
- ◆ discuss the competency frameworks that should be considered when practitioners provide advice line services
- ◆ highlight limitations in services, including how the needs of minority ethnic or cultural groups may not be adequately served by routine telephone advice
- ◆ provide examples of appropriate documentation and supporting legal issues that should be considered when providing telephone advice line services
- ◆ provide a resource with useful links and telephone numbers, additional reading and references for those wanting to develop their services.

The RCN hopes that the collaborative approach to improving care taken in this guidance will be the first of many initiatives focusing on the needs of those with LTCs.

Using the guidance

Practitioners should use this guidance in the context of the local needs of their own patient group and service provision, and within local and national NHS policy, including clinical governance frameworks. We recommend that specialist practitioners, particularly those working with individuals with LTCs, develop disease-specific information to support this document. Website links can be found in Appendix 9.

Each section of the document identifies the research evidence and grades it according to the Royal College of Physicians' guidelines (2003). The working party has attributed recommendations to each section and graded these based on research evidence and working party consensus. We recognise the value of measuring service and caller outcomes, but given the scope of this

document we ask practitioners to refer to the key references to support the brief outline provided in here.

It has been suggested that as a result of the rapid growth of telephone consultations, future disease-specific guidelines should include information related to assessment and appropriate advice following a telephone consultation (Car and Sheikh, 2003; Car et al., 2004). Although this is not covered in this guidance, we recommended that practitioners consider these issues when extending the scope of telephone services.

Guidance is not provided in this document for:

- ◆ surgical pre-treatment or triage telephone services
- ◆ systems to replace primary care consultations or accident and emergency call out services
- ◆ computer assisted telephone services (such as NHS Direct)
- ◆ telephone consultations in place of routine follow-up appointments
- ◆ email or web-based interactive support services
- ◆ mobile phone texting
- ◆ patient-led charitable organisation telephone services.

This document may be a useful reference point for registered nurses employed by charitable organisations. Practitioners may also find it helpful to refer to examples of the work that patient organisations can provide to complement those provided by the specialist units.

For further information see Section 6 and Appendix 7.

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Methodology

Contributors

The RCNRF recognised that the lack of current guidance on providing telephone advice services is not unique to musculoskeletal services. A working party was set up to develop this guidance document, inviting contributions from a wide range of specialists and practitioners from other specialist fields of practice who care for individuals with LTCs.

The RCNRF also asked patient-led organisations to contribute. Patient-led organisations provide valuable telephone support, which complement services provided by health care professionals to ensure that individuals are empowered to manage their conditions effectively. These organisations have a wide perspective on the needs of their members and they are increasingly involved in all areas of health care provision, including telephone advice lines.

Additional participants contributed by reviewing the work via email. These participants included specialist nurses working in various health care settings, reflecting the diversity of needs of the patient groups across the UK. The consultation process enabled review and feedback on draft versions and highlighted additional issues for consideration. Appendix 10 gives a full list of working party members and the lead email contributors.

Reviewing evidence for the document

Although the evidence base for telephone support is limited, it was essential that a rigorous approach to reviewing the available literature was applied.

The evidence base was reviewed using the AGREE Guidelines (AGREE Collaboration, 2001) and Royal College of Physicians' Concise Guidelines (RCP, 2003 – see Appendix 3).

Where there was limited evidence, expert opinion was sought by working party consensus. Also included are audits and abstracts that may be of particular interest to readers. These are identified in evidence review by a hash sign (#) to ensure readers are aware that these do not fit the full grading criteria.

References to the research/papers used are given throughout the text. Some sources are not directly related to simple telephone advice lines for individuals with LTCs, but cover innovative aspects of care (such as telephone triage and telephone consultations) replacing

outpatient follow-up services. These references have been added as a resource for the reader.

A full list of the references is given in Appendix 1 and a table showing the grading criteria and grading of all evidence used in developing the document is given in Appendix 3.

Background to the development and efficacy of advice lines

For a review of the evidence in this area, see Appendix 4.

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Principles of good practice

Good communication

The principles of good communication apply to all consultations, but nurses/practitioners must be mindful that aspects of normal communication – visual prompts, gestures and physical contact – are missing from telephone consultation. Before providing telephone support, nurses should have demonstrated their competency in undertaking consultations in routine care.

For a successful telephone consultation, it is important to have:

- ◆ a conducive environment with minimal distractions and background noise
- ◆ patient confidentiality/privacy throughout the consultation
- ◆ good equipment to ensure appropriate sound quality
- ◆ access to documentation/record keeping and, where available, electronic patient records
- ◆ an empathetic manner, including reassurance and reiteration of the issues to confirm the callers concerns and needs
- ◆ sufficient time available to acquire the necessary information from the caller, ensuring sound clinical decision-making
- ◆ the ability to provide clear and concise advice with guidance.

What the telephone consultation should cover

Key information

The caller's name, date of birth, hospital number or address, telephone number, usual partner/carer and permission to discuss information with partner/carer should a return call be required.

Clear advice and guidance

Covering:

- ◆ what the caller and nurse/practitioner have agreed is the current problem and the specific advice that they seek
- ◆ clarification of the diagnosis and current treatment, monitoring or recent medical interventions/problems/dates of future outpatient appointments
- ◆ 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
- ◆ any specific social or psychological issues that may make the caller more vulnerable and require additional support or rapid access to key services (e.g. cognitive impairment, mental health problems, or frail elderly)
- ◆ clarity and agreement on the steps necessary to resolve the problem or seek further help
- ◆ time frame for self-management strategies if advised, when to review the success of such strategies and who should review them
- ◆ what the caller should do if problems continue
- ◆ a mutually agreeable time to return a call if a follow-up is planned. Agreement about who will instigate the review call
- ◆ review of decisions and closing call with clear outline of plan.

Safety of advice

It cannot be over emphasised that that there should be clarity about the aims and objectives of the service. The remit of the nurses/practitioners providing the support should also be clearly defined. In particular, nurses should be clear about their remit regarding changes of treatment or dosages and supporting documentation.

All health care professionals providing support to patients should be aware of the advice line and the services that can be provided to patients and other health care professionals. Patients using the service should be aware of the sources of information available to them and the topics covered.

At times verbal advice provided on the advice line may need to be supported by correspondence (to teams providing care or sometimes the patient themselves) outlining the plan following the consultation.

Specific protocols for safety of advice that practitioners must consider (Lattimer et al., 1998), backed up by an agreed framework for practice, relate to:

- ◆ changes of treatment – advice that can be given and documentation (see Section 7)
- ◆ informing the specialist or primary care team, (or others involved in the patient's care) of any advice/problems reported and advice given

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Setting up a service

- ◆ documenting any referrals to other teams/specialist practitioners and planned feedback or outcomes
- ◆ pathways to ensure efficient referral to other health care professionals following call
- ◆ clinical supervision for nurses/practitioners
- ◆ guidance on difficult calls and resolving telephone complaints
- ◆ closing the consultation down.

Medication

Taking a routine clinical history can sometimes be difficult, even in the usual clinical outpatient setting. When undertaken by telephone, it can be even more difficult. Nurses/practitioners should:

- ◆ establish what evidence they have readily available about the caller to support the telephone discussion (e.g. electronic records or rudimentary information)
- ◆ ask the patient to have their repeat prescription documents in front of them or their bottles and packets of medication at hand, so the caller can spell these out to the practitioner, providing precise information regarding dose and frequency
- ◆ gather more information about medications, including any blood monitoring booklets or information related to other outpatient appointments the caller has booked. Also consider any specialist interventions that may be relevant to medications (for example, do they have a planned surgical intervention that might necessitate stopping treatment?)
- ◆ take into account nurse prescribing clinical management plans, and the remit of the advice line with regard to changing callers' medications over the telephone
- ◆ add appropriate and prompt documentation to the patients' records, if procedures do allow for medication changes over the phone, so that all practitioners have access to the information. The caller's primary health care team must be informed of any changes made.

Managing expectations and needs of evolving services

To date, telephone support has been incorporated into the daily workload of nurse specialists. For many, the first step to developing an advice line would have been the introduction of answerphone system purely to manage the increasing demands on their time for informal telephone support.

Studies have explored the value of direct response over answerphone systems and demonstrated mixed results (Thwaites et al., 2003; Brownsell and Dawson, 2002). How expectations are changed and managed are difficult factors to evaluate. However, in recent years many changes to service provision have resulted in a reduction of telephone support, usually because of insufficient staffing or high clinical demand.

Informing users

As services evolve, problems are created by failure to advise patients about the scope of service and what to expect in the way of response and waiting times for a return call.

When establishing or changing a service:

- ◆ provide verbal and written information to individuals on:
 - the use of telephone advice and what to expect (for example, time to respond to a call left on an answerphone)
 - the type of advice and support that can be provided
 - other contacts for information/support, (for example, patient-led telephone support or outpatient appointments number)
- ◆ consider ways in which the patient can receive adequate education about their disease and recognise the value of enhancing their self-management strategies, so that the telephone helpline becomes an integral tool in their self-management, rather than increasing their reliance on the advice service

- ◆ consider how to avoid the potential risks related to the occasional circumstances when individuals might use the advice line in emergency situations. This may be because they are familiar with the service and team. Sometimes this can happen after a failed attempt at self-managing their condition. This scenario should be avoided, as emergency calls require a rapid response and may require additional training and competencies for practitioners to manage the call effectively.

Practitioners' expectations

There is little data exploring practitioners' perspectives on providing telephone support (Holmstrom et al., 2002). One study explored practitioner opinions when looking at the provision of helplines (Brown et al., 2006). Some disparities were identified between professionals' views, and those of the callers, particularly in relation to the times of advice line availability. Patient users recommended the service be available during office hours, seven days a week, whereas the service providers suggested that availability five days a week would be adequate, and some said they would prefer email rather than telephone correspondence.

Planning and managing a service

Practitioners planning a service need to reflect on issues highlighted here and shape local provision based on a range of factors including the specific needs of those who will use the service.

This guidance is not intended to be prescriptive, but this section will prompt you to identify factors to consider. It includes suggestions for planning the infrastructure and the possible resource needs of a service. The needs of callers will vary depending upon other support structures available to them as well as other equality and diversity issues.

Setting up a telephone advice line must be planned and implemented in collaboration with the multi-professional team and local patient groups. An effective advice line service requires access to medical input to ensure that nurses are adequately supported should complex problems arise from a telephone call that require medical expertise to resolve or manage.

Practical issues in setting up and managing a service

There are number of key issues to consider. These include:

- ◆ the potential need for such a service
- ◆ current service provision and impact of waiting times
- ◆ exploring the needs and expectations of likely users
- ◆ access for potential users to other support services (for example, through patient organisations)
- ◆ additional specialist support available. For example, is there access to general practitioners with a special interest (GPwSI), or practitioners with a special interest (PwSI) in the community, or other rapid access support such as interface clinics providing support for exacerbations of users' condition?

Aims and practice of the service

Establish clearly the remit and practice of the service, by considering:

- ◆ the aims and objectives of the service, reaching a consensus with colleagues on how the advice line services will function
- ◆ how to ensure information about the service and its aims and objectives are clearly explained to potential callers
- ◆ how information about the service will be disseminated
- ◆ whether the advice line will be a direct response or answerphone service
- ◆ times of availability – e.g. 9am-5pm Monday to Friday or 24 hour service supported by ward staff or other team members?
- ◆ how soon will calls be returned and episodes completed?
- ◆ how will 'non-standard' calls be managed? For example, private patients or patients who call who are not your own specialist department, or dealing with distressed patients
- ◆ will the service handle emergency calls?
- ◆ how to manage and where to refer patients not covered by the advice line service (for example, guidance on how to deal with suicidal calls)
- ◆ whether support will be provided to relatives and carers
- ◆ what advice will be provided to the caller about seeking help when the advice line is closed
- ◆ will the service provide specific information about other useful numbers (e.g. for outpatient appointment queries)?

The needs of the community

When setting up an advice line, you will need to establish the geographic, social, cultural and health/disability needs of the community who will use the service.

Consider:

- ◆ the patient population (for example, a busy and compact city community or a rural community, a largely elderly age distribution)
- ◆ specific impairment, language or ethnic/cultural issues that need to be considered in using the telephone.

You may need to consider informing different groups about the service and whether it is possible for the individual (or their family/carers) to access the service on a patient's behalf. Consider:

- ◆ would an answerphone message need to be in an additional language?
- ◆ will an interpreter be required?
- ◆ does the service provide equity of access for all? Look in particular at the hearing and visually impaired (particularly when preparing literature to advise of the service and what the service can provide)
- ◆ are there services you could access to increase user-friendliness. For example, the Royal National Institute for the Deaf provides an assisted telephone package called 'type talk' for the hearing impaired. For more information visit www.typetalk.com

Resources

You will need to cost and provide:

- ◆ competent staff and ongoing training/clinical supervision needs
- ◆ back up systems; for example, provision for leave, particularly if it is a single-handed nurse/practitioner service
- ◆ adequate time to deal with calls, document and communicate outcomes
- ◆ types of phone
- ◆ access to paper or computerised patient records
- ◆ clerical support for filing and retrieving and notes, routine administration tasks etc.
- ◆ suitable office environment
- ◆ access to appropriate medical support/services to resolve difficult issues promptly (e.g. specialist or primary care support)
- ◆ reviewing and updating relevant support literature
- ◆ computerised patient record keeping.

Use of telephones

Consider for your telephone or answerphone:

- ◆ the use of direct response or answerphone systems
- ◆ use of voicemail and content of message. The use of remote 'voicemail facility' might be helpful for practitioners who are not always based in the unit where the advice line facility is located
- ◆ digital or tape-recording facility or answerphone
- ◆ whether it will be staffed at specific times with dedicated timeframes for taking calls
- ◆ number of days and times the service is provided
- ◆ standards for answering/returning calls.

Patient support services

Voluntary organisations may be able to provide complementary support to those of an advice line service, and information about these services should be included in any patient information literature.

Examples of charitable organisations' advice lines are given in Appendix 8 and telephone helpline association training links are listed in Appendix 9.

When you are establishing your service, find out about other telephone services available, making sure you understand their aims and objectives and their competency frameworks, to ensure that you will be recommending patients to appropriately resourced and trained services.

Setting out a business case

It may be helpful to prepare a business case to identify:

- ◆ current resources and practice – who takes calls at the moment?
- ◆ costs involved in setting up and running an advice line – it is not just the cost of the telephone
- ◆ potential cost savings to the trust/primary care trust as a result of having an advice line
- ◆ projected development of the service and plans to support the increasing calls

In costing the service, or demonstrating potential efficacy, factor in the potential costs and resources saved by service provision, quality of life and patient care issues, as well as the direct costs for the service itself. Consider:

- ◆ costs related to the required resources, and benefits, e.g. cost savings (see example on page 10)

- ◆ changes in service and patient outcomes as a result of telephone advice line support. For example:
 - reduction in requests for outpatient or GP consultation to resolve problems
 - support provided to primary care teams through advice line service
 - ◆ waiting times for, and availability of, urgent review appointments (cost of consultation versus costs of issues resolved by phone)
 - ◆ concordance, documentation and risk management issues (e.g. changes in medication resolved following telephone queries, drugs stopped due to side effects)
 - ◆ patient satisfaction, 'self efficacy' and empowerment issues
 - ◆ quality of life indicators (e.g. prompt relief of pain).
- Time needs to be factored into the case, as an 'advice line call' is not only the time spent speaking to the caller on the first occasion. Time may be spent calling up or collecting notes, x-rays or investigation results, speaking to colleagues, arranging interventions, documenting the call and possibly a number of attempts to contact the patient by telephone in return.

Assessing the costs of advice line services and cost savings: an example based upon paper by Hughes et al., (2002)

Factor	Potential Cost (approximate, for demonstration purpose only)
Digital telephone with answerphone	£50
Training costs (1 day course) per person	£150 (run by the Telephone Advice Lines Association)
Time-staff costs (including 'on-costs' *)	
Nurse	£16.93 per hour midpoint Band 6 £20.14 per hour midpoint Band 7
Clerical support	£9 per hour midpoint Grade 3
Telephone calls out	5p per minute local calls (includes line rental) Higher costs to mobile phones
Visit to GP (9.36 minutes)	£21
Telephone consultation with GP (10.8 minutes)	£24
Cost of hospital outpatient follow-up clinic visit	£91 (national tariff, varies with specialty)

* 'on-costs' are calculations to include employer costs, e.g. holiday, sickness cover, room costs. Consult trust guidance on additional costs that need to be included.

Costs calculated using *Unit Costs of Health & Social Care* (Curtis and Netten, 2004).

Salaries for nursing (www.rcn.org.uk) and allied healthcare professionals can be found on the Department of Health website (www.dh.gov.uk). Please remember these costs do not include employers' on-costs and general overheads. The cost of outpatient visits can be reviewed at the Department of Health website, *Payment by results core tool 2004*. Information for Scotland can be sought from www.show.scot.nhs.uk and Wales www.wales.nhs.uk and Northern Ireland www.n-i.nhs.uk

These figures are likely to change and therefore it is important to check these when preparing a business case.

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Service provision

Here are some more examples of ways you could demonstrate the potential benefits to the patient and reduction in financial/resources as a result of providing an advice line.

Scenario 1

Call to advice line (20 minutes of nurse time – includes speaking to patient, documentation and resulting action, no doctor intervention) = £5.64

Cost of FU visit = £91

Saving to hospital trust per episode = £85.36

Scenario 2

1,531 calls received in a year by a rheumatology department, with 60% of callers going to GP if advice line had not been available.

60 per cent of 1,531 calls = 908 calls

Cost of one visit to GP = £21

Cost of 908 visits to GP = 908 x £21 = £ 19,068 p.a.

Advice line call = 20 minutes of nurse time

908 calls = 303 nurse hours (@£16.93 per hour)
= £ 5130 p.a.

The amount of time required for clerical support will vary according to hospital systems and infrastructure. Analyse average time per call and calculate time related to administrative support. Deduct this cost from final saving to primary care.

Saving to primary care = £13,938 p.a.

Staffing and time management

Consider:

- ◆ cost analysis of time allocated and banding of staff providing support
- ◆ assessment of routine workload and development issues
- ◆ clerical support
- ◆ documentation
- ◆ time frames for returning calls and resolving queries
- ◆ access to appropriate medical support/services to resolve difficult issues promptly (e.g. specialist or primary care support).

Clerical support:

- ◆ dedicated clerical support
- ◆ training and support to ensure safe and effective clerical expertise
- ◆ time to manage notes, retrieving and filing of notes
- ◆ support for some routine administration of the service.

Agreed framework for practice

Make sure that your team have and follow an agreed framework for practice, covering key areas such as:

- ◆ level of decision-making
- ◆ general patient advice and/or disease-specific or treatment advice; for instance, monitoring of blood results, or changing drug dosages
- ◆ communicating treatment changes and advice given
- ◆ documentation for notes
- ◆ agreement on plan of action or information provided
- ◆ review process.

Succession planning

The sustainability of the advice line is dependent upon good business planning. It is essential that services are adequately resourced with time to manage the service as well as the nurses to support it. However, it has to be recognised that many services currently provided have been developed from the good will of nurses who have evolved advice lines from an increasing number of telephone calls to their department. In some circumstances practitioners are working in isolated roles. This has implications for continuity of service, particularly for providing cover during annual leave, sickness and training, but ultimately also for succession planning.

In these circumstances it is essential to inform the trust of the service and ensure that providing this support is included in a practitioner's job description. It may also be necessary to document the practitioner's expertise in the form of training and competency in supporting people by telephone. This is of particular relevance when delegating or training new members of staff to support the advice line service.

Evaluation and audit

Advice line services must be audited and reviewed to ensure that it is adequately providing for patient needs and is safe and cost effective.

If the aims and objectives of the service are clear and you set achievable standards, these will provide a focus for business planning and any future changes in provision.

To evaluate the service, look at:

- ◆ patient and practitioner outcome measures, audit and research:
 - why the advice line is used?
 - what is expected from the service?
 - what benefits are gained?
 - what are the limitations to the service provision?
- ◆ time taken to provide the service:
 - number of callers using the service – on a monthly basis and annually
 - cost benefit analysis.

Standards set for the advice line services should be audited. Audits maybe required for different purposes, but some examples could include:

- ◆ review of efficiency of service based upon standards set (for example, the number of calls that were returned within the specified standard set)

- ◆ evaluation of reduction in callers requesting GP consultations
- ◆ nurse time on advice line calls
- ◆ reduction in emergency admissions (might be related to early proactive management of problems)
- ◆ number of referrals to rapid access or urgent review clinics via advice line.

Audit tools are available for many different specialist areas, for example:

- ◆ NHS organisations have audit departments who can provide expert advice on devising specific audit tools and support to analyse the data
- ◆ members can access RCN specialist forums (www.rcn.org.uk) for guidance on their specialist field and review standards of care to measure. We hope that following the publication of this guidance, forums will prepare their own specific information to support this document
- ◆ professional or patient groups.

7

Governance issues

Risk management

Consider whether:

- ◆ job descriptions reflect telephone advice line work
- ◆ infrastructures safely support the service (e.g. clerical support, time frames to resolve issues, documentation)
- ◆ the remit of advice line and service outline are clearly documented
- ◆ succession planning is in place to ensure competent staff support service
- ◆ critical incident reporting is in place
- ◆ regular review and analysis of workload is undertaken
- ◆ clinical supervision for health care professionals is provided, particularly supporting practitioners following difficult calls.

Legal issues

There are a number of professional and legal issues for practitioners to consider when providing any form of health care support, and these principles remain as relevant when providing telephone advice.

These will include policies on:

- ◆ documentation
- ◆ confidentiality
- ◆ risk management
- ◆ statutory training
- ◆ professional codes of conduct (NMC, 2004b, 2005)
- ◆ prescribing practice
- ◆ complaints and governance procedures.

Practitioners should ensure that their employer is informed about the service provided and endorse the work undertaken on the telephone advice line service. In the case of NHS trusts, this means the role and competencies of the practitioner providing the advice line service must be outlined in the individual's job description. Vicarious liability will also mean that standards procedures as outlined in trust policies must also be adhered to.

Consider:

- ◆ the trust's vicarious liability – where will the service be provided and do current job descriptions support such a development? It may be appropriate to review job descriptions if the service is a new development or if it is an initiative that is extended to another geographical area (for instance in the community setting) (Dimond, 2002)

- ◆ ensuring practitioners work within and refer to codes of professional conduct and record keeping (NMC, 2004b, 2005)
- ◆ whether the employing trust has a sound knowledge of the range and scope of the service
- ◆ whether there are national or local standards that should be considered and referred to
- ◆ standardised assessment sheets and record keeping are in place. These may help transparency and ensure a rigorous and methodical approach to the service. If there are no local policies, seek advice from governance representatives with your organisation
- ◆ training and competency frameworks ensure practitioners are adequately trained. How do they maintain their competency? Each practitioner must be able to demonstrate their level of expertise (Coleman, 1997)
- ◆ patient awareness of the service. Is the information effectively spread to ensure equity of access for all?
- ◆ is communication with caller concise and information clearly understood (verbal and written when required)? A potential area of risk and legal claim will be when there is a failure in communication or a misunderstanding of instructions. The telephone consultation must be supported by effective structures to ensure that the patient and the practitioner are clear of plans and follow up care if required. This should be supported by appropriate documentation and may require communication with other health care professionals following the consultation
- ◆ there are effective and agreed lines of communication with the team and supporting practitioner. Patients should be made aware that you may need to talk to other health care professionals regarding advice and treatment changes
- ◆ confidentiality is maintained. As well as confidentiality of patient information, there may be additional points to consider: for example, do you have permission to leave messages for patients, and do they consent to information being shared with a relative/carer/partner?
- ◆ complaints procedures are in place. How will the patient complain about the service if they are not happy with their care? It may be appropriate to add information to the patient information leaflet, or your trust may have separate supporting documents and mechanisms to handle patient complaints.

Documentation

Keeping accurate and up to date documentation is an essential part of a nurse's role. Remember that documentation is essential for legal purposes, to demonstrate clarity of decision-making, advice provided and plan for follow up (where appropriate). The information recorded may also be vital to ensure high quality care and reduce risks related to poor communication, either within a specialist team or by other practitioners involved in the caller's care. You will need to establish and maintain good practice for managing:

- ◆ information on the telephone message system, and how it is recorded. Consider and discuss storage of data in accordance with local trust policies and data protection guidance
- ◆ informing the patient of the service – type of information, timing of provision etc. Ensure that patients are made aware of how you communicate outcomes
- ◆ proforma or protocol?
- ◆ recording treatment changes and any other outcomes of telephone consultation
- ◆ recording outcomes of telephone consultation
- ◆ clarity of interpretation and outcomes for patients/review
- ◆ complaints procedures
- ◆ audit.

Training and competency

Nurses and allied health care professionals must work within their recognised professional codes of conduct and competency frameworks.

Training for staffing advice lines should be given in addition to key clinical skills in practitioners' specialist field of practice. Health professionals and patient-led organisations should ensure that they are appropriately trained to provide telephone advice, including the use of non-visual communication skills. These skills should enable the telephone interviewer to acquire relevant clinical and general information, provide prompts when necessary to encourage the caller, and give clear, succinct and empathetic responses (Pettinari and Jessopp, 2001). Practitioners should also have access to clinical supervision to ensure that they are adequately supported and can cope with the stressors related to telephone consultations (Severinsson and Kamaker, 1999).

Telephone interview skills can improve clinician performance, confidence and ultimately patient satisfaction (Payne et al., 2002; Car et al., 2004).

Core competencies/key aspects of training should include:

- ◆ good clinical decision-making skills, including sound knowledge of the disease area and treatment options
- ◆ sound knowledge of potential risks related to the disease and treatments
- ◆ communication skills – interview techniques (listening and questioning skills) and coping with difficult calls (see Section 8)
- ◆ skills to gain appropriate information without visual clues
- ◆ limitations of telephone consultation and patient recall
- ◆ legal implications of telephone advice.

Training should also be supported by adequate clinical supervision.

Practitioners should also be competent in identifying important indications that may require urgent medical referral (these specific problems are often referred to as 'red flags'). It is vital that practitioners have the expertise to recognise any issues that should be considered a 'red flag' in general care, but also within their field of practice.

Further reading can help develop expertise in understanding the transition from novice to expert in clinical management and developing specific consultation skills. For example, Benner (1984) is a key text defining the development from novice to expert.

8

Clinical issues

Promoting self-management not reliance

To help develop the service as a tool of self-management, rather something on which callers become increasingly reliant, make sure that:

- ◆ the service provides clear frameworks that encourage callers' confidence in quality and standards of the service
- ◆ there is clarity of aims and objectives, so practitioners and callers know what can and can't be achieved using the advice line
- ◆ infrastructure and resources to support advice line needs are available (e.g. emergency access clinics to manage symptom control or rapid access to services)
- ◆ the service complements, not replaces, primary care and medical support
- ◆ advice line support is seen as an integral part of patient education and to support self-management strategies.

Returning calls

There are times when there are difficulties in returning a call or resolving a problem arising from an initial call. It is therefore essential that callers are aware of how the services will function, the time frame for return of calls (including number of attempts to return calls) and most importantly that the service does not provide emergency advice. This information should be clearly stated on the telephone service recorded message, as well as in patient information leaflets about the service. All standards set must be realistic and achievable.

If a caller leaves their name and telephone number on an answerphone system, services can consider this implied consent to return the call using the number provided. It will be worthwhile setting out on your literature/answerphone system, what procedure you will follow when returning a call. For example, if the nurse has tried three times to return the call without being able to contact the caller, the outcome will be recorded in the notes as 'unable to contact after three attempts' and no further return calls will be made.

If the call is answered by someone else (other than the patient) a brief explanation should be given to enable access to the patient without compromising patient confidentiality.

Some patients' telephones may have a facility that blocks calls that attempt to access them without a recognised telephone number. As many NHS trusts' switchboards routinely 'withhold' their number when dialling out, you will need to contact the hospital switchboard to request they remove the 'number withheld' facility temporarily so you can make the return call.

Managing time-consuming calls

Occasionally there will be callers who have complex needs and wish either to call the advice line frequently, or, when they call, require a large amount of time to outline their problems. This can present a significant challenge for nurse and the advice line service, particularly when the service may only be provided for a limited period each day. Such circumstances can be stressful for both caller and nurse (Wahlberg et al., 2003).

It is also possible that providing an endless amount of listening time may not be the most effective support for the caller. It may also compromise the access of other callers trying to get through. You will need to make sure your practitioners promote empowerment and not reliance, and consider:

- ◆ reviewing the telephone interview style you use and seek advice in structuring the telephone consultation. This requires managing the initial query in an empathetic way, listening to caller's problems/needs, collecting relevant clinical information to guide decision-making, refining the issues, reiterating decisions made with the caller, drawing the call to a close with an agreed outline plan of actions (reiterated clearly to the caller)
- ◆ making sure callers have access to clear statements about the service in the patient information leaflet that can improve service provision
- ◆ outline the valuable additional support from charitable organisation advice lines and discuss the type of support they can provide
- ◆ setting up specific outpatient appointments to devote appropriate time to assessing the caller's needs or referral to other specialist, charitable or community services to provide the support they require; for example, a caller with financial problems may benefit from an appointment with the Citizens Advice Bureau
- ◆ ensure the team have access to good clinical supervision.

Limitations of telephone advice lines

Weaknesses in provision

Telephone advice lines should be seen as an important service, integral to supporting and educating the caller through a problem solving process as part of the advice given.

However, telephone advice services do have limitations, which you must be aware of and guard against. Some of these relate to:

- ◆ services that have evolved with no formal infrastructure
- ◆ poor management of expectations and needs of patients, relatives and fellow professionals
- ◆ promoting reliance on telephone support
- ◆ patient groups who find the use of telephones difficult (e.g. hearing-impaired or elderly people)
- ◆ reliance on the patients' recall and on reported rather than observed changes in signs and symptoms
- ◆ access to key information may not be available at the time of the call
- ◆ failure of callers to comply with advice provided
- ◆ lack of advice line capacity to respond to languages other than English
- ◆ problems returning calls
- ◆ poor procedures for closing calls down
- ◆ dealing with verbal abuse
- ◆ dealing with complaints
- ◆ poor confidentiality
- ◆ governance issues.

Difficulty in using telephone advice line support

There are a number of circumstances when telephone advice alone cannot safely resolve the problem. These include difficulties in interpretation of the presenting signs and symptoms (for example a skin rash) where the patient might be advised to stop their treatment until they have been examined. A facility for appropriate rapid access service should be available and agreed as part of the overall planning of the advice line to ensure patient needs are met.

Services must provide adequate facilities and time to ensure that the environment is conducive to exploring the patient's specific problems. Key information should be given clearly and a mutual agreement of the outcomes and decisions related to the telephone interview should be confirmed by both the nurse and

the caller. There may be restrictions to the level of information that can be provided over the phone if the nurse does not have access to the patient records at the time of the call.

The service may not be able to provide special support for some patient groups, particularly those with cognitive impairment, hearing or language barriers. Health care teams should be aware of these limitations and make alternative provision to support these individuals.

9

Conclusion

This guidance document provides an initial framework for nurses/practitioners who provide telephone advice line services for individuals (and their families/carers) with LTCs. Practitioners should seek additional information from specialist fields of practice to supplement this generic document.

It is important to recognise that telephone advice lines play an important role in enhancing self-management and supporting individuals with LTCs. Advice lines also play a pivotal role in accessing prompt advice and support when attempts to self manage fail or urgent guidance is required.

In recent years innovative approaches in the management of LTCs have also used the telephone to provide consultations and reviews of treatment. Nurses and practitioners interested in extending their services may wish to explore innovative approaches to supporting the individual and enhancing service provision. (The appendices include some useful links that will be of help for those wishing to access additional information).

10

Appendices

Appendix 1: References

Note: publications which are particularly recommended reading are asterisked*. You should also ensure you consult local and trust policies on finance, etc.

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Appendix 3: Grading of evidence used in this document

The RCN Rheumatology Forum reviewed the evidence base for this document using the AGREE Guidelines (AGREE Collaboration, 2001) and Royal College of Physicians' Concise Guidelines (RCP, 2003).

Level of evidence chart: Abbreviated from the RCP guidance, 2003

Type of evidence	Grade
Meta analysis of randomised controlled trials (RCTs)	A
At least one RCT	A
At least one well designed controlled study but without randomisation	B
At least one well designed quasi-experimental design	B
At least one non-experimental descriptive study	B
Expert committee report, opinions and/or experience of respected authorities	C

The working party reviewed evidence published in the field of LTCs, using the following search criteria and search terms:

- ◆ timeframe: 1982-2005
- ◆ terms searched: helplines, telephone helplines, advice lines, nurse helplines, nurse-led telephone helplines, hotlines, telephone advice hotlines, telephone advice
- ◆ search engines used: CINAHL, BNI, MEDLINE, OVID, Cochrane Library, Dialog Dastatar, Proquest, King's Fund.

Table: Graded evidence used in telephone advice services for people with LTCs

Evidence	Level of evidence			
	A	B	C	#
1. Ashcroft, 1999			✓	
2. Brown et al., (in press 2006)		✓		
3. Brownsell and Dawson, 2002 (poster)				✓
4. Bunn et al., 2004 (Cochrane)	✓		✓	
5. Car et al., 2004			✓	
6. Car and Sheikh, 2003			✓	
7. Coleman, 1997			✓	
8. Cornell et al., 1999 (poster)				✓
9. Cornell, Thwaites and Oliver, 2004			✓	
10. Hewlett et al., 2000	✓			
11. Hewlett et al., 2005	✓			
12. Holstrom and Dall'Alba, 2002		✓		
13. Hughes et al., 2002		✓		
14. Kennedy et al., 2004	✓			
15. Lattimer et al., 1998	✓			
16. Marklund et al., 2001				
17. McCabe et al., 2000				✓
18. Nightingale et al., 1999	✓			
19. Payne et al., 2002		✓		
20. Pettinari and Jessopp, 2001		✓		
21. Severinsson and Kamaker, 1999		✓		
22. RCN, 1999			✓	
23. Robinson et al., 2001	✓			
24. Telephone Helplines Group, 1993			✓	
25. Thwaites et al., 2003 (poster)				✓
26. Twomey C, 2000				
27. Thwaites, 2004		✓		✓
28. Walhberg et al., 2003		✓		

Appendix 4: An overview of the evidence: the development and efficacy of advice lines

The earliest evidence of providing support to individuals using telephones was that provided by the Reverend Chad Varah in 1953 in the development of the Samaritans (Cornell et al., 2004). Since that time, telephone use has grown dramatically in all areas of life and is increasingly being used as a valued patient resource.

In 1997, NHS Direct was introduced: a nurse-led, 24 hour, advisory telephone service. Its service aimed to provide immediate advice to callers using computerised decision systems to promote self-help and reduce demand on the emergency services and primary care (DH, 1997). NHS Direct is now established throughout the UK and employs experienced nurses who assess the calls using computer assisted devices (Commission for Health Improvement, 2002). NHS Direct is an important resource for the general population, although it is perceived that such services may have limited value for those with LTCs requiring specialist ongoing support.

There is evidence that individuals with an LTC, their carers and health care professionals value telephone helpline services (Ashcroft, 1999; Bunn et al., 2004; Brown et al., 2005). If adequately funded and planned, advice lines can be a cost effective means of communication between specialist services, the patient and other non-specialist health care professionals providing care.

Evidence demonstrating the use of telephone advice lines in the management of long term diseases include: cardiology (Lindsay, 1995), oncology (Twomey, 2000), rheumatology (Hughes et al., 2002) urology (Langley, 1995), chronic pain (Crawley and Webster, 1998) inflammatory bowel disease (Nightingale, Middleton and Middleton, 1999). Additional information evaluating the use of service is limited and chiefly consist of audits, or studies of patient satisfaction and preferences between staffed and answerphone services (Brownsell and Dawson 2002; Hughes et al., 2002; Thwaites et al., 2003). In surveys high levels of patient satisfaction have been identified (Ashcroft, 1999; Brownsell and Dawson, 2002).

Innovation in telephone advice services has recently improved the quality and provision of care for those receiving ongoing, follow-up care. For example, individuals whose condition is stable can now request their next appointment in place of a regular outpatient review (Hewlett et al., 2000). The Hewlett study

demonstrated that individuals who actively took part in managing their rheumatoid arthritis experienced a reduction in pain and an increase in self-efficacy and satisfaction. A similar study on patients with inflammatory bowel disease (IBD) (Kennedy et al., 2004) reflected a similar outcome, with no increase in GP visits, a reduction in relapses (16 per cent) and no changes to anxiety or quality of life. This level of support is clearly a step up from traditional telephone support for a specific group of individuals requiring general advice (Bunn et al., 2004).

A randomised controlled trial of individuals with ulcerative colitis (Robinson et al., 2001) studied the outcome of teaching patients with chronic conditions skills in self-managing a flare up with no further routine clinic (or telephone) follow-up appointment. Those participants in the intervention group – using the new telephone support – preferred the telephone intervention to ‘usual’ follow-up care (only two of the 101 intervention group patients preferred ‘usual’ care). A further study exploring telephone access for inflammatory bowel disease found that only 8 per cent of calls required an outpatient appointment following telephone support (Nightingale, Middleton and Middleton, 1999).

When evaluating such interventions, however, we do need to consider the type of support provided, as some issues may well affect the outcomes. For example, is follow-up care integral to the service provided? What additional level of previous disease-specific education have individuals had before they participate in telephone review services?

It has been suggested that as a result of the rapid growth of telephone consultations future professional disease-specific guidelines should include information related to the assessment and appropriate advice following a telephone consultation (Car and Sheikh, 2003; Car et al., 2004). Although this is not covered in this guidance it is recommended that practitioners consider these issues when extending the scope of telephone services.

Appendix 5: Example patient information sheet

Note: ensure the format matches agreed local policy (e.g. font and trust header).

<p>The Rheumatology Telephone Advice Line</p> <p>Telephone number: [insert number]</p> <p>Name of practitioner/s:</p> <p>Aim of the rheumatology telephone advice line service</p> <p>The purpose of this service is to provide advice and support for patients with rheumatological conditions attending the [insert hospital name].</p> <p>The advice line is not an emergency service</p> <p>If you require urgent medical advice you must contact your GP surgery [leave blank to insert number] or attend your local accident and emergency department.</p> <p>When should you call the advice line?</p> <p>You should call the advice line:</p> <ul style="list-style-type: none"> ◆ if you experience a reaction to an injection given at the rheumatology clinic ◆ if you have a 'flare up' of your condition that has not improved with your usual self-help treatments ◆ if you are experiencing side effects which you feel may be caused by the medication prescribed for your arthritis ◆ if you have concerns about your symptoms or management that need to be addressed before your next appointment. 	<p>How does the advice line work?</p> <p>The advice line is an [answerphone/direct response service]*. Please leave the following information on the answerphone:</p> <p>[*delete as appropriate and add any additional information re. times available etc.]</p> <ul style="list-style-type: none"> ◆ your full name ◆ your hospital number or date of birth ◆ a telephone number where we can contact you ◆ the reason for your call. <p>A senior rheumatology nurse will listen to your message and return your call, within [insert number of days or specify days] working days.</p> <p>If you are out when the nurse returns your call, only two further attempts will be made to contact you. If you still require advice you will need to contact the advice line again.</p> <p>Who may use the advice line?</p> <p>This service is available to patients who attend the rheumatology department at the [insert hospital/unit]. Your relatives may also call with your permission. Confidential issues will only be discussed with you. Your own doctor and other health care professionals can also access the advice line</p> <p>If you need to change an appointment please ring the appropriate number:</p> <table border="0"> <tr> <td>Rheumatology appointments</td> <td>[insert number]</td> </tr> <tr> <td>Podiatry appointments</td> <td>[insert number]</td> </tr> <tr> <td>Occupational therapy</td> <td>[insert number]</td> </tr> <tr> <td>Physiotherapy</td> <td>[insert number]</td> </tr> </table>	Rheumatology appointments	[insert number]	Podiatry appointments	[insert number]	Occupational therapy	[insert number]	Physiotherapy	[insert number]
Rheumatology appointments	[insert number]								
Podiatry appointments	[insert number]								
Occupational therapy	[insert number]								
Physiotherapy	[insert number]								

Appendix 6: Example telephone advice line card

[Specialist area]
Telephone advice line
[Telephone number]

Name of practitioner(s): _____

The advice line is available between: _____
[stipulate time/days]

Calls will be returned within: _____ **working days.**

Please leave your name, contact number and a brief message.

The advice line is not an emergency service – contact your GP or emergency services .

Appendix 7: Examples of call sheets

Telephone contact sheet and patient contact record form	
Unit name:	Date:
For the attention of:	Call taker:
Returned call: [if answerphone document, note number of return calls if unable to contact patient]	Answer/direct response:
Patient's name:	Date of birth:
Telephone number:	Hospital number:
Known relevant history:	Diagnosis:
Today's problem:	Returned call: Attempted: <input type="checkbox"/> Comment:
Current/recent medication:	Last OPA:
Action:	Next OPA:
Initials of team: <input type="checkbox"/> SPR <input type="checkbox"/> AHP	Other:
Referral made: <input type="checkbox"/> OPD <input type="checkbox"/> DN <input type="checkbox"/> GP <input type="checkbox"/> AHP <input type="checkbox"/> Palliative care team <input type="checkbox"/> Investigations	
Patient understanding of next step:	Actions: Review:
Contacted by: At:	Date and time:
Signature:	

Appendix 7: Examples of call sheets

Date of call:	Time:	Duration of call:
Name of person receiving call:		
Caller:	<input type="checkbox"/> Patient	<input type="checkbox"/> Relative
	<input type="checkbox"/> GP/practice nurse	<input type="checkbox"/> Other
Patient name:	M/F:	
Hospital number:	usually reviewed by RNP/Dr/AHP	
Date of birth:		
Age range:	<input type="checkbox"/> 0-18	<input type="checkbox"/> 19-30
	<input type="checkbox"/> 31-45	<input type="checkbox"/> 46-55
	<input type="checkbox"/> 56-65	<input type="checkbox"/> 66-79
	<input type="checkbox"/> 80+	
Telephone number:	Mobile number:	
Reason for call		
<input type="checkbox"/> Rheumatoid arthritis	<input type="checkbox"/> Osteoarthritis	<input type="checkbox"/> Systemic lupus erythymatosus
<input type="checkbox"/> Psoriatic arthritis	<input type="checkbox"/> Ankylosing spondylitis	<input type="checkbox"/> Other
<input type="checkbox"/> Worsening symptoms	<input type="checkbox"/> Require earlier appointment	<input type="checkbox"/> Results query
<input type="checkbox"/> Drug side effects	<input type="checkbox"/> Earlier appointment	<input type="checkbox"/> Other
<input type="checkbox"/> Verbal advice	<input type="checkbox"/> Other	
Outcome of call:		
Discussed with:		
<input type="checkbox"/> Nurse	<input type="checkbox"/> Practitioner	<input type="checkbox"/> Doctor
	<input type="checkbox"/> AHP	
<input type="checkbox"/> Intra muscular depo medrone	<input type="checkbox"/> Seen out of clinic	<input type="checkbox"/> Given earlier appointment
<input type="checkbox"/> Verbal advice	<input type="checkbox"/> Other	
Signature:		

Appendix 8: Examples of patient organisation advice line services

Arthritis Care

Arthritis Care provides a free, confidential information and support service to people with all forms of arthritis, their friends, family and carers, and to professionals. The service is provided by telephone, letter and email. About 54 per cent are first time callers and all these will have received a basic pack of information tailored to their condition and personal circumstances. *The Source* is Arthritis Care's helpline service particularly aimed at young people or the parents of young children. For details, telephone 0808 808 2000 or email the source@arthritiscare.org.uk

The helpline team are drawn from various professional backgrounds but all have qualifications in counselling and telephone helpline experience. Many of them have arthritis themselves, and this helps them to understand the challenges that living with arthritis can pose. They receive ongoing training, supervision and support to ensure that the services they provide continue to be professionally delivered and of a high standard. Arthritis Care is a member of the Telephone Helplines Association and has been awarded their Quality Standard accreditation. The service also adheres to the British Association for Counselling and Psychotherapy guidelines.

Service aims:

- ◆ facilitate the empowerment of people with arthritis.
- ◆ provide accurate information about all aspects of living with arthritis
- ◆ provide emotional and practical support
- ◆ to act as a contact and signposting point to other agencies/service.

Contact details:

Telephone: 0808 800 4050 (freephone, available weekdays 10am to 4pm)
 Email: Helplines@arthritiscare.org.uk
 Website: www.arthritiscare.org.uk

The Continence Foundation

The Continence Foundation's helpline is open 9.30am to 1.00pm on weekdays, normally staffed by one continence nurse specialist, but two lines can be used when busy. An answerphone system operates when the line is busy or the call is not answered. Sickness and holidays can be covered by a nurse working from home and dialling into the answerphone. The number starts with 0845 which means that callers pay the price of a local call from anywhere in the UK.

Nurses answer questions about any aspect of bladder or bowel control in adults (calls about children are generally passed on to a sister charity). If a nurse cannot answer a question, she will ask the helpline manager to call the person back or seek information from the continence service where she works for the rest of the week. If the person seeking advice has not contacted their local continence service, there will usually be a recommendation to do so. A database of all NHS continence advisers is maintained on the service website and is searchable by the postcode of the potential patient. The Foundation also has a database of all continence products available in the UK. Nurses send out the Foundation's information leaflets (and some from other organisations) as appropriate. Calls are also received from professionals.

All staff have received specialist training in continence – minimum nursing Grade F when they start, but will be expected to rise to G or H. Clinical supervision is provided by the continence service which holds their main contract – their contract with the Foundation is for 1 or 2 half days. (Locums used are people known to be experienced.) All staff are expected to attend courses to maintain their clinical knowledge and/or to be studying for further qualifications. During their probationary period, they will attend a course with the Telephone Helplines Association.

Aims and objectives of the Continence Foundation:

- ◆ to raise awareness about bladder and bowel problems
- ◆ to foster education and promote research
- ◆ to provide information, advice and expertise
- ◆ to influence policy-makers and providers of services (public and private)
- ◆ to co-operate with other charities and with professional organisations.

Contact details:

Telephone: 0845 345 0165
 Email: continence-help@dial.pipex.com
 Website: www.continence-foundation.org.uk

The National Rheumatoid Arthritis Society (NRAS)

NRAS provides support and information for people with rheumatoid arthritis, their families and carers

Helpline

Telephone: 0845 458 3969
Email: enquiries@rheumatoid.org.uk
(Open between 10am and 4.30pm Monday to Friday.)

The team provide total support and information on all aspects of living with rheumatoid arthritis. Sometimes a sympathetic ear is necessary; often information on a particular aspect of rheumatoid arthritis is required, eg. drug treatments, blood tests. Medical advice is not provided, although NRAS has a team of rheumatology consultants and health professionals to whom Helpline staff refer specific questions.

National Volunteer Support Network

Telephone: 01628 823524 and ask for Support Network Team
Email: supportnetwork@rheumatoid.org.uk

Volunteers are spread across the UK and all have rheumatoid arthritis. The aim is for NRAS volunteers to provide local telephone support to enable individuals to get support where and when they need it. Wherever possible people are matched by age and circumstances as well as location.

NRAS website

www.rheumatoid.org.uk

This is packed with news and information about all aspects of living with rheumatoid arthritis as well as information on drug and new developments.

NRAS members Internet forum

Exclusively available to members of NRAS, it is the place for those who like to use the Internet to communicate with others about living with rheumatoid arthritis.

Charity aims:

- ◆ provide a support and information service on all aspects of the disease
- ◆ raise public and government awareness of rheumatoid arthritis
- ◆ campaign for more funding to be made available for treatment of the disease
- ◆ facilitate the networking of patients and encourage self-help.

Appendix 9: Telephone and website resources

Arthritis Research Campaign

www.arc.org.uk

Arthritis Care

www.arthritiscare.org.uk

Association of Independent Care Advisers

Provides help to older people and disabled people of all ages and their families.

www.aica.org.uk

Telephone: 01483 203066

Back Care

Charity for healthier backs.

www.backcare.org.uk

Telephone: 08709 500275

British Association for Counselling and Psychotherapy (BACP)

www.bacp.co.uk

Telephone: 0870 443 525

British Association of Dermatologists

www.bad.org.uk

British Lung Foundation

www.lunguk.org

British Pain Society

www.britishpainsociety.org.uk

British Society for Rheumatology and British Healthcare Professionals Allied to Rheumatology

www.rheumatology.org.uk

CancerBACUP

Support for people who live with cancer.

www.cancerbacup.org.uk

Telephone: 0808 800 1234

Carers online

Information and support to professionals, relatives and friends who are carers.

www.carersonline.org.uk

Telephone: 0808 808 7777

Hours: Monday to Friday, 10am-12pm and 2-4pm

Commission for Patient and Public Involvement in Health

www.cppih.org

Continence Foundation

www.continence-foundation.org.uk

Department of Health

www.dh.gov.uk

Diabetes Association

www.diabetes.org.uk

Disabled Living Foundation

www.dlf.org.uk

Telephone: 0845 130 9177

Electronic British National Formulary

www.bnf.org

Frank Campaign Helpline

Provides information and support services on drugs and information on local services. The service can take calls in over 120 languages via a three way call on local services.

www.dh.gov.uk/ContactUs/InformationPhoneLines

Hours: available 365 days a year 24 hours a day

Help the Aged

www.helptheaged.org.uk

Telephone: 0808 800 6565

Hours: Monday to Friday, 9am-4pm

King's Fund, London

www.kingsfund.org.uk

Long Term Medical Conditions Alliance

www.lmca.org.uk

Lupus UK

www.lupusuk.com

Medicines.org.uk

Access to patient information leaflets and summary of product characteristics.

www.medicines.org.uk

MENCAP

www.mencap.org.uk

Learning disability helpline: 0808 808 1111

Multiple Sclerosis Trust

www.mstrust.org.uk

National Asthma Helpline

Telephone: 0845 701 0203

Hours: Monday to Friday, 9am-7pm

National Electronic Library for Health

Provides links to all aspects of healthcare and evidence based resources.

www.nelh.nhs.uk

National Rheumatoid Arthritis Society

www.rheumatoid.org.uk

Nephronline

www.nephronline.co.uk

NHS Modernisation Agency

www.modernnhs.uk

Nursing and Midwifery Council

www.nmc.org.uk

OKA

Telephone assistance for hearing impaired.

www.typetalk.com

Pain Network

For nurses, health care workers and patients.

www.painnetwork.co.uk

Pain-talk

Discussion forum for health care professionals with an interest in acute, chronic or palliative pain management.

www.pain-talk.co.uk

Parkinson's Disease Society

www.parkinsons.org.uk

Telephone: 0808 800 0303

Hours: Monday to Friday

Prodigy Knowledge

Clinical knowledge and evidence related to conditions and symptoms managed by primary health care professionals.

www.prodigy.nhs.uk

Psoriatic Arthritis Alliance

www.paalliance.org

Raynaud's and Scleroderma Association

www.raynauds.org.uk

Renal Association

www.renal.org

Royal College of Nursing

www.rcn.org.uk

Royal College of Nursing Research Link

www.man.ac.uk/rcn

Scleroderma Society

www.sclerodermasociety.co.uk

The Asian Health Agency

www.taha.org.uk

Warwick University Centre for Research in Ethnic Relations

The major academic body in the UK for the research and teaching of aspects of race, migration and ethnic relations.

www.warwick.ac.uk/crer

Appendix 10: Working party members

Name	Qualifications	Representing	Organisation	Vested interests
Sue Brown Clinical Nurse Specialist in Connective Tissue Diseases	MSc, RGN, EN (G)	British Healthcare Professionals for Rheumatology (BHPR) South West England Research Group	Royal National Hospital for Rheumatic Diseases NHS Foundation Trust, Bath	Partially funded by Lupus UK and Raynaud's and Scleroderma Association: provide national advice to their members via hospital helpline
Maggie Carr Consultant Nurse	MSc, DPSN, RGN	Ashford & St Peter's Hospital NHS Trust	Ashford and St Peter's Hospital NHS Trust	None
Trish Cornell Senior Rheumatology Practitioner	RGN, BSc (Hons)	RCNRF	Poole Hospital NHS Trust, Dorset	None
Janet Kimble Nurse Specialist UGI	RGN	RCN Gastroenterology and Stoma Care Forum Barrett's Oesophagus Foundation	Royal Hampshire County Hospital, Winchester	None
Jill Hill Diabetes Nurse	BSc (Hons), RGN	RCN Diabetes Forum	Eastern Birmingham Primary Care Trust	Two shifts per week specialist for Novo Nordisk diabetes helpline
Christine Norton Nurse Consultant	PhD, MA, RN	RCN Gastroenterology and Stoma Care Forum	St Mark's Hospital	None
Susan Oliver Nurse Consultant Rheumatology LEAD AUTHOR	MSc, RGN	RCNRF	Litchdon Medical Centre, Devon	None
Cath Thwaites Lecturer in Rheumatology Nursing	RGN, ONC, Dip N	RCNRF	School of Nursing and Midwifery, Keele University Rheumatology Centre, Stoke-on-Trent, Staffordshire	None

Email reviewers

Name	Qualifications	Representing	Organisation	Vested interests
Linda Caie Parkinson's Disease Nurse Specialist	RGN, SCM, MSc Nursing	The Parkinson's Disease Nurse Specialist Association RCN Nurses Scotland	NHS Grampian	None
Chris Cox Solicitor Assistant Director of Legal Services		RCN	RCN	
Janice Mooney Course Director and Lecturer Practitioner	RGN, MSc	University of East Anglia RCNRF	University of East Anglia, Norwich	None
Elizabeth McIvor Rheumatology Nurse Specialist	RGN, RSCN, MSc	Stobhill Hospital RCN Nurses Scotland	Stobhill Hospital, Glasgow	None
Elaine Williams Rheumatology Nurse Practitioner	RGN, BSc Nursing (Hons)	RCNRF	North Cheshire Hospital NHS Trust, Warrington, Cheshire	None
Suzanne Morris Clinical Nurse Specialist for Rheumatology	RGN, MSc Health Studies	RCN Nurses Wales	Withybush General Hospital, Haverfordwest, Pembrokeshire	None
Liz Thomas Senior Pharmacist	B.Pharm (Hons), MRPharmS	Pharmacists	University Hospital Birmingham NHS Foundation Trust	None
Dawn Homer Nurse Consultant	RGN, MSc	RCNRF	Selly Oak Hospital, Birmingham	None
Elaine Wylie Rheumatology Nurse Specialist	RGN, BSc (Hons), PGDip	RCNRF	Green Park Healthcare Trust, Rheumatology Unit, Belfast, Northern Ireland	None
Cath Brownsell Specialist Nurse	RGN, BA (Hons)	RCNRF	St Helen's and Knowsley NHS Trust, St Helens	None
Sheena Hennell Nurse Consultant	RGN, MSc	RCNRF	Wirral Hospital NHS Trust, Arrow Park Hospital, Merseyside	None

Patient organisations

Name	Qualifications	Representing	Organisation	Vested interests
Helen Bunyan Membership and Administration Manager		NARS	NARS	None
Jo Cumming Helplines Manager	MA	Arthritis Care	Arthritis Care	None
Dr Judith Wardle Director	PhD	Continence Foundation	Continence Foundation	None



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