

Production of an information leaflet on diabetic peripheral neuropathic pain

Samantha Davies and David Coppini

Article points

1. Diabetic peripheral neuropathic pain (DPNP) presents a challenge to the multidisciplinary diabetes team, who have to determine the best treatment option as well as manage individuals' expectations of pain relief.
2. The provision of an information leaflet on DPNP educates individuals and their families about the condition, outlines therapeutic options available and informs about potential side effects.
3. Better education on DPNP empowers individuals to manage their condition effectively.

Key words

- Diabetic peripheral neuropathic pain
- Education
- Information leaflet

Samantha Davies is a Diabetes Nurse Specialist with an interest in painful neuropathy; David Coppini is Consultant Diabetologist, Department of Diabetes, Poole Hospital NHS Foundation Trust, Poole, Dorset.

Diabetic peripheral neuropathic pain (DPNP) affects between 16 and 26% of all people with diabetes (Daousi et al, 2004), and its management presents enormous challenges to the multidisciplinary diabetes team. Successful intervention depends on managing individuals' expectations, establishing realistic goals for pain relief and minimising adverse events. The authors produced a patient information leaflet in order to address the need for written information on DPNP as a complimentary tool in the specialist clinic. The leaflet outlines DPNP using common and lay-term pain descriptors and highlights therapeutic options available. Educating individuals ensures they have realistic expectations about their pain relief, understand the treatment options available, are knowledgeable about possible side effects and feel supported. Education through information leaflets offers advice and support and leads to better treatment adherence (Blinder et al, 2001).

Although the complications of diabetes are well recognised, diabetes as a cause of chronic pain is less well known. Diabetic peripheral neuropathic pain (DPNP) affects between 16 and 26% of all people with diabetes, and evidence suggests that the condition is under-diagnosed, under-treated and, more importantly, generally under-reported by individuals affected (Daousi et al, 2004). In hospital-based studies the prevalence of DPNP ranges from 11 to 20% (Boulton et al, 1985).

DPNP has a serious significant negative impact on individuals' quality of life, affecting mood and self-esteem, often hindering good-

quality sleep and sometimes leading to severe anxiety and depression. Its chronicity may also affect mobility and independence, ability to work and interpersonal relationships (Mendell and Sahenk, 2003). These resulting problems highlight the importance of providing a source of adequate information for individuals who are particularly debilitated by this condition.

The management of DPNP presents enormous challenges to the multidisciplinary diabetes team. Multifactorial issues to be considered include:

- Individuals' expectations of adequate pain relief and their tolerance of prescribed medications often lead to disappointment.

- Individuals' education on their diagnosis, natural history and treatment is crucial in helping to establish realistic goals and expectations at an early stage.

Current therapies for painful sensory neuropathy result in, at best, a 30–50% reduction in pain intensity, and such a reduction only rarely meets individuals' expectations (Boulton et al, 1985). Informed decision-making and consent are vital components of modern clinical practice, but are known to be more effective when complemented with easy-to-comprehend written information (Greenwood, 2002).

Information provision

There are two basic ethical principles that underpin the necessity for healthcare professionals to provide adequate information: the first is the ancient Hippocratic Oath, "to do what is best for the patient"; the second is a more recent concept of respecting patient autonomy, emphasising the right for the individual "to have full control over anything done to his or her body" (Ziegler et al, 2001).

Providing individuals with information has been a priority on the political and nursing agenda for many years. Over a decade ago, the government addressed the issue by stating that hospitals should "offer clear and sensitive explanations of what is happening on practical matters, such as where to go and who to see, and on clinical matters, such as the nature of an illness and its proposed treatment" (Department of Health [DH], 1989; Greenwood, 2002).

The *Patient's Charter* (DH, 1992) and subsequently the *Priorities and Planning Guidance for the NHS* (NHS Executive, 1997) further stressed the importance of providing patient information. These documents expressed a need for healthcare professionals to actively involve patients in any decisions about their health, as well as encouraging them to participate in their care (Greenwood, 2002).

More recently the NICE (2010) guidelines for the treatment of neuropathic pain also highlight that treatment and care should take into account individuals' needs and

preferences. Good communication is essential, and should be supported by evidence-based information aimed to help individuals make sensible and informed decisions about their care.

To address these issues, the authors have developed a simple information leaflet in an attempt to improve the overall quality of care provided to individuals affected by DPNP.

Leaflet development

Individuals with DPNP in the authors' unit are referred to a consultant diabetologist with a specialist interest in DPNP. Although the focus of the clinic visit is on a detailed explanation of DPNP and its management, there are often other presenting problems or complications, including foot problems and other diabetes complications, poor glycaemic control and abnormal lipid and blood pressure measurements. The co-existence between poor foot sensation and pain is somewhat counter-intuitive, and individuals with diabetes may consider lower-extremity pain to be unrelated to their diabetes and therefore fail to report it to their healthcare professional. Furthermore, reporting pain, especially DPNP where there is no obvious or ongoing external cause, may be associated with feelings of self-doubt, weakness, embarrassment or even a fear of being stigmatised (Lillrank, 2003).

Coulter (1998) reports that individuals often want to understand the cause of the problem and its treatment options; they often enquire about possible self-help measures, requesting balanced information about the risks and benefits of treatment (Turnbull, 2003). In addition, although relatives or carers may be unable to attend clinic appointments, they may also request information regarding DPNP.

Various checklists have been proposed to enhance the quality of health information, including:

- Accessibility.
- Acceptability.
- Readability.
- Comprehensibility of information.

Page points

1. NICE (2010) guidelines for the treatment of neuropathic pain highlight that treatment and care should take into account individuals' needs and preferences; good communication is essential, and should be supported by evidence-based information aimed to help individuals make sensible and informed decisions about their care.
2. To address these issues, the authors have developed a simple information leaflet in an attempt to improve the overall quality of care provided to individuals affected by DPNP.
3. Various checklists have been proposed to enhance the quality of health information, including: accessibility, acceptability, readability and comprehensibility of information.

“Drug options in our leaflet are clearly highlighted in order to familiarise individuals with common medications, and a brief explanation of how they work is also given. Effective pain treatment consists of a favourable balance between pain relief and adverse events; the medication the authors have outlined as treatment options in their leaflet reflect this.”

The style and attractiveness of presentation, its accuracy and its reliability of content are also important (Coulter, 1998).

The authors produced a patient information leaflet in order to address the need for written information on DPNP as a complimentary tool in the specialist clinic. As there are few leaflets on DPNP available, no other leaflets were reviewed in this process. The trust’s department of clinical governance produced some obligatory guidance and restrictions on the leaflet, which underwent a review by the patient advice and liaison services team. During this process the leaflet was available on the hospital intranet and could thus be viewed by colleagues. This process also ensures that all patient leaflets are regularly reviewed and updated. In addition, leaflets can be adapted to suit other languages and texts.

The authors’ leaflet was also pilot-tested by five people with diabetes and DPNP who were asked to evaluate the content, including the terminology used, its “friendliness” and its overall usefulness. The review tool was a generic patient feedback questionnaire issued by the patient advice and liaison services team. Results of the pilot study were favourable and the feedback from the patient advice and liaison services team was positive, so no changes were made to the leaflet.

Every team developing patient information tools needs an expert with knowledge of customary procedures, practices and protocols. However, individuals’ information needs may not be satisfied by what experts decide to tell them (Turnbull, 2003), and despite experts’ good intentions, the information is not necessarily of high quality and useful to the individual (Slaytor and Ward, 1998).

Information on DPNP

The authors’ leaflet aims to offer a basic explanation of DPNP and uses common and typical lay-term pain descriptors commonly associated with neuropathic pain. As there are currently no pharmacological cures for neuropathy, this point is made clear at an early stage in the leaflet, before treatment options for DPNP are discussed. The authors felt

that it was paramount to address individuals’ expectations in the first paragraph of the leaflet, not only with regards to their condition but also with respect to pain relief, expected onset of action and the likelihood of side effects.

Little is known on the amount of information individuals want to know on the risks of adverse drug reactions; healthcare professionals continually face the problem of how much detail to give on this subject. Ziegler et al (2001) aimed to determine whether individuals felt that physicians should use discretion in the amount of information they give. Their findings suggest that most individuals desire full information concerning possible adverse effects of prescribed medication, and do not favour physicians’ discretion in these decisions.

Drug options in our leaflet are clearly highlighted in order to familiarise individuals with common medications, and a brief explanation of how they work is also given. An explanation that the drugs used for DPNP are often used for other medical health conditions is also documented. This helps lessen confusion and reduces the likelihood of false assumptions, for example that individuals must also be suffering from depression because they have been prescribed antidepressants.

Therapeutic options

DPNP may constitute a considerable management problem; at best, current therapies result in a 30–50% reduction in pain, and such a reduction rarely meets individuals’ expectations (Boulton et al, 1985). Treatment of DPNP presents enormous challenges and is currently felt to be inadequate. Individuals expect substantial pain relief with relatively few side effects; failure to meet these expectations often leads to some disappointment. The efficacy of a single therapeutic agent is not the rule, and simple analgesics are usually inadequate to control the pain. Therefore, various therapeutic schemes have been previously proposed, but none have been properly validated. Nonetheless, there is a general agreement that individuals should

be offered the available therapies in a stepwise approach. Effective pain treatment consists of a favourable balance between pain relief and adverse events (Finnerup et al, 2005). The medication the authors have outlined as treatment options in their leaflet not only reflect this but also are in accordance with recent regional prescribing guidelines for DPNP.

In the authors' experience, individuals are often commenced on drug therapies without a robust system of follow-up being provided. This often results in individuals stopping the drug after only a few days, either because immediate pain relief was not experienced or as a result of side effects; patient information leaflets are intended to help prevent either of these happening. A warning on the importance of avoiding the sudden cessation of long-term medication is also included in the leaflet.

Reassurance and support

For most people illness is a source of anxiety, but it has been demonstrated that understanding the condition and treatment enhances both the recovery and the ability to cope with a situation, such as living with chronic pain. However, readiness to learn is an accepted and well-documented phenomenon. It is essential that people are given the opportunity to do so at their own pace and at a time that is right for them (Lowry, 1995). In the authors' opinion this also emphasises the importance of regular follow-up clinic appointments for this group of people. Relevant healthcare professionals' contact details are included in the conclusion of the leaflet, so that individuals feel supported.

Patient-centred approach

The current literature generally supports the use of information leaflets, stating that they improve individuals' knowledge about their condition, treatments available and potential side effects of drugs used (Gibbs et al, 1990). Although shared decision-making by individuals and clinicians has been advocated, little is known about the degree of

participation in decision-making, with regards to both individuals' actual preferences and clinicians' appreciation of such preferences (Gibbs et al, 1990). A study by Strull et al (1984) found that clinicians underestimate individuals' desire for information and discussion, but overestimate their desire to make decisions; awareness of this discrepancy may facilitate communication and decision-making.

Individuals forget between 40 and 80% of medical information provided by healthcare professionals (McGuire, 1996). The greater the amount of information presented, the lower the proportion that is correctly recalled. Furthermore, almost half of the information that is remembered is incorrect (McGuire, 1996). The form or mode of information delivery is also highly relevant. In most instances, medical advice is spoken, but this is not the most successful method (Thomas et al, 2001); written information is better remembered and leads to better treatment adherence (Blinder et al, 2001). However, written instructions do present difficulties to individuals with low education or literacy and to non-native speakers, so other options have to be made available. The authors feel that it is important to remember that most leaflets, regardless of their topic, require relatively high reading skills that may not exist in a large proportion of their target population. Thus many people may not be able to comprehend important aspects of information leaflets because of their content, writing style or organisation (Payne et al, 2000). If there was any doubt in the individual's comprehension of the leaflet, the authors endeavoured to deliver the information verbally; transferring this information onto a CD may be a consideration for the future. The need for a patient-centred approach to providing information is evidently paramount.

Conclusion

The growth and wider availability of the Internet greatly increases access to health information. A large number of health-related websites exist, and over a third of Internet

Page points

1. For most people illness is a source of anxiety, but it has been demonstrated that understanding the condition and treatment enhances both the recovery and the ability to cope with a situation, such as living with chronic pain.
2. The current literature generally supports the use of information leaflets, stating that they improve individuals' knowledge about their condition, treatments available and potential side effects of drugs used.
3. However, most leaflets, regardless of their topic, require relatively high reading skills that may not exist in a large proportion of their target population. Thus many people may not be able to comprehend important aspects of information leaflets because of their content, writing style or organisation.

“Pain is a complex experience that depends strongly on cognitive, emotional and educational influences. The authors’ information leaflet is intended to compliment the verbal information that is used to help individuals understand their condition and to provide realistic expectations of the treatment options available.”

users access the web in order to retrieve health and medical information. Most of this material is inaccurate or misleading (Payne et al, 2000), which further highlights the need to provide accurate, robust information that is easily accessible and meets the needs of individuals.

Pain is a complex experience that depends strongly on cognitive, emotional and educational influences. The authors’ information leaflet is intended to compliment the verbal information that is used to help individuals understand their condition. An additional aim of the leaflet is to provide realistic expectations of the treatment options available. The intended end-result is to ultimately help empower the individual suffering with DPNP, an important goal that should in itself have a positive therapeutic effect on this difficult complication of diabetes. ■

Copies of our leaflet can be obtained by emailing: David.Coppini@poole.nhs.uk or Samantha.Davies@poole.nhs.uk.

Blinder D, Rotenberg L, Peleg M, Taicher S (2001) Patient compliance to instructions after oral surgical procedures. *Int J Oral Maxillofac Surg* **30**: 216–19

Boulton AJ, Knight G, Drury J, Ward JD (1985) The prevalence of symptomatic diabetic neuropathy in an insulin-treated population. *Diabetes Care* **8**: 125–8

Coulter A (1998) Evidence-based patient information is important, so there needs to be a national strategy to ensure it. *BMJ* **317**: 225–6

Daousi C, MacFarlane IA, Woodward A et al (2004) Chronic painful peripheral neuropathy in an urban community: a controlled comparison of people with and without diabetes. *Diabet Med* **21**: 976–82

Department of Health (1989) *Working for Patients*. The Stationery Office, London

Department of Health (1992) *The Patient’s Charter: Raising the Standards*. The Stationery Office, London

Finnerup NB, Otto M, McQuay HJ et al (2005) Algorithm for neuropathic pain treatment: an evidence-based proposal. *Pain* **118**: 289–305

Gibbs S, Waters WE, George CF (1990) Prescription information leaflets: a national survey. *J Roy Soc Med* **83**: 292–7

Greenwood J (2002) Employing a range of methods to meet patient information needs. *Prof Nurse* **18**: 233–6

Lillrank A (2003) Back pain and the resolution of diagnostic uncertainty in illness narratives. *Soc Sci Med* **57**: 1045–54

Lowry M (1995) Knowledge that reduces anxiety: creating patient information leaflets. *Prof Nurse* **10**: 318–20

NHS Executive (1997) *Priorities and Planning Guidance for the NHS: 1998–99*. NHS Executive, London

NICE (2010) *Neuropathic Pain: The Pharmacological Management of Neuropathic Pain in Adults in Non-Specialist Settings*. NICE, London. Available at: <http://www.nice.org.uk/nicemedia/live/12948/47949/47949.pdf> (accessed 04.07.12)

McGuire LC (1996) Remembering what the doctor said: organisation and older adults’ memory for medical information. *Exp Aging Res* **22**: 403–28

Mendell JR, Sahenk Z (2003) Painful sensory neuropathy. *N Engl J Med* **348**: 1243–55

Payne S, Large S, Jarrett N, Turner P (2000) Written information given to patients and families by palliative care units: a national survey. *Lancet* **355**: 1792

Slaytor E, Ward J (1998) How risks of breast cancer and benefits of screening are communicated to Australian women: analysis of 58 pamphlets. *BMJ* **317**: 263–4

Strull WM, Lo B, Charles G (1984) Do patients want to participate in medical decision making? *JAMA* **252**: 2990–4

Thomas AM, Cunningham SJ, Hunt NP (2001) A comparison of information retention at an orthodontic consultation. *Eur J Orthod* **23**: 169–78

Turnbull A (2003) How nurses can develop good patient information leaflets. *Nursing Times* **99**: 21–6

Ziegler DK, Mosier MC, Buenaver M, Okuyemi K (2001) How much information about adverse effects of medication do patients want from physicians? *Arch Intern Med* **161**: 706–13