

Patient information and the role of the carer

Introduction

Information for patients is integral to patient care and this is also so with day surgery (Ley, 1998; Thornes, 1991).

Vulnerable clients – children, young people, the elderly, and those who are physically disabled, mentally ill or have learning disabilities – have needs which should receive specific attention. More time may be needed to explain to them what is going to happen during the day, and to support and educate parents/carers in providing care in the day unit and at home. Liaising with colleagues who have appropriate expertise with the client group may be valuable.

Government guidance on the care of children and young people in hospital (DH, 1991; Scottish Office, 1993, DH, 2002) and legislation concerning children (DH, 1989; DHSS N. Ireland, 1995; Scottish Office, 1995) should be incorporated into practice in both the NHS and independent sector (RCN, 2000).

Information is as important to the parent/carer as it is to the patient. This information sheet covers two topics that are essential to the successful completion of a day surgery episode:

- ◆ patient information
- ◆ the role of the parent/carer.

Patient information

Written information is essential for patients and their parents or carers as a back up to verbal information. Written information given in advance helps a patient, parent or carer to plan ahead. It allows them to consider how going into hospital for surgery will impact on work and social schedules, and family life as a whole. Information can give details about when to stop eating and drinking before surgery, post-operative recovery and return to daily living activities.

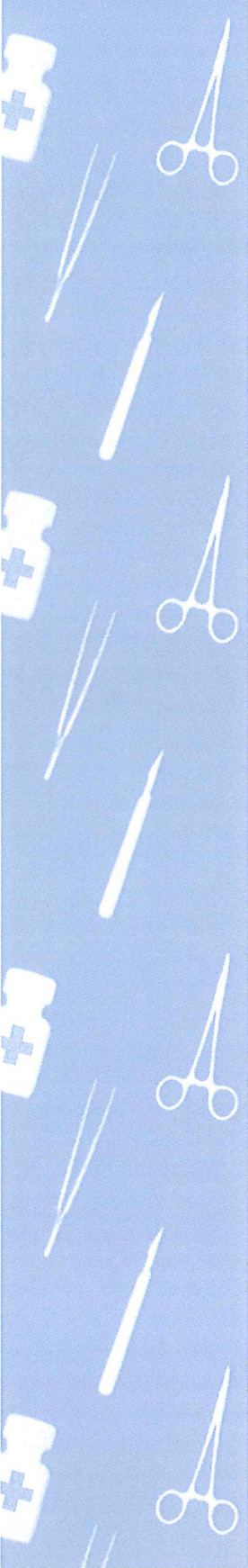
When producing a patient information leaflet you should canvas the views of the people you are writing for. First, write down all the questions that patients and parents/carers ask about their condition, treatment and follow-up care. Then write down the answers to all of these questions and structure them so that they describe the patient's experience.

Written information must be in a language that is familiar to the reader and at a level they will understand. The information should include:

- ◆ Details of a pre-admission programme or unit visit for children and young people which they can attend with parents in preparation for admission. Seeing the environment and meeting staff members as part of a pre-admission programme reduces anxiety for children undergoing day surgery and their parents/carers.

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- ✦ Procedure information – why surgery is needed, what the operation involves, recovery after surgery, pain control, how to care for a child at home, returning to school and/or normal activities, possible problems.
 - ✦ Information about clinical risk – for example risk of perforation in termination of pregnancy. Discuss this with the clinicians and the clinical risk manager or medico-legal department in your trust.
 - ✦ General anaesthetic information – how patients will react and feel after having an anaesthetic. (Determine this with the day surgery consultant anaesthetist.) Information on fasting times and the importance of following the timed instructions, as well as the use and effects of local topical anaesthetic creams.
 - ✦ Information about the day unit and their stay:
 - ◆ the unit's telephone number, and directions to the hospital and ward
 - ◆ support with transport if required
 - ◆ what time to arrive
 - ◆ what to bring and what not to bring into hospital
 - ◆ how long they may have to wait
 - ◆ a guide to the length of stay
 - ◆ what will happen to them or their child while they are in day surgery
 - ◆ who they will see, and
 - ◆ the parent's or carer's role in providing care.
 - ✦ What to expect after surgery. This should cover:
 - ◆ a general guide to the recovery period
 - ◆ time needed off work for patients, parents and carers
 - ◆ pain control and wound care
 - ◆ return to work/nursery/school and leisure activities for patients
 - ◆ exercise and mobility
 - ◆ diet
 - ◆ post-operative blues
 - ◆ useful contact numbers should they need advice before admission, and help and community support once discharged.

When writing patient information use the correct clinical terminology, but also a more familiar term (plain English). It is important to explain everything in simple language but it is also important not to insult your reader. Clinical terms may need to be clarified and tailored to avoid words that might be frightening to the reader, such as "needle".

When structuring post-operative information it is useful to use daily living activities as a guide, adapting these for each client group. These will give details about rest, pain control, eating and drinking, bathing, work, school, driving and resuming sexual activities. Parents of children/young people undergoing day surgery need information tailored to meet their child's requirements.

Once you have what you think is an adequate draft, printed in size 12 font (minimum), give it to someone who is not employed in a clinical or health care profession. Ask them if they understand it and if it gave them enough information. It is also useful to use a reading score to test its readability – for example the Flesch Reading Ease Score (1947). The Plain English Campaign (www.plainenglishcampaign.com) has useful advice and publications to help get information across clearly.

Once you have made any adjustments, you are now ready to pilot it with the people for whom it is intended. Following this, you need to evaluate its effectiveness and amend the information.

Consider the ethnic and cultural diversity within the population served by your trust. The same information should be available to all patients in a language that they can read. Remember that sensitive information may not translate well and the meaning of some words may be lost or altered significantly.

It is also important to remember that not everyone can read, and that audio- or videotapes can be used for communicating the same information. Simple diagrams are also helpful when describing information about procedures involving parts of the body – for example where the skin may be punctured or cut.

It may be helpful to distribute copies of the information to general practitioners, community nurses, children's community nursing teams, health visitors and schools so that they are aware of the



information you give to patients and their families.

Finally, review information sheets regularly and amend accordingly.

The role of the parent/carers

Carers need information about their role and what to do if they experience any difficulties.

Government guidance in the four UK countries states that parents/carers should be closely involved at all times in the care of children/young people undergoing day surgery (DH, 1991; Northern Ireland, 1995; DH, 2004).

Parents and carers have a key role in supporting the child throughout the whole experience, both before admission, in hospital and at home. They therefore need information and support.

Preparation and information giving should begin as soon as the need for surgery is decided. Written information can be given in outpatients and from the day unit, and the family can be invited to visit the unit.

"Parents who are involved, informed, communicated with, advised specifically and who feel cared for and cared about, will be more confident and capable of being partners in care through the hospitalisation and recovery process of their child" (Darbyshire, 2003).

A video or slideshow depicting the story of the day's events from admission to discharge is a useful introduction. It reinforces the role of the parent/carers in preparing for surgery before admission, and for their role as carers both on the day and at home following surgery. Ideally this should take place on the day unit and include information on: travel to and from hospital; arrival time; estimated length of stay; what to bring; explaining the procedure to a child; fasting times for solids and fluids; the order of the day; who they will see; the anaesthetic, the operation; pain control; discharge planning and support at home; recovery and time off school/work.

The role of the informal carer after day surgery is relatively unexplored. However, following a qualitative piece of research (Haynes, 1999) the advice below is recommended:

- ◆ Invite parents/carers to attend the pre-operative assessment of the patient.

Alternatively, hold a carer's evening in your unit/ward, where their role can be discussed and any concerns they have addressed. Some units caring for children/young people have an organised pre-admission programme held after school or at weekends. This gives the child and parents/carers an opportunity to express any fears or anxieties, to meet staff and become familiar with the environment, and to learn their role in preparing for the procedure.

- ◆ Introduce a verbal reinforcement policy that ensures all written information is discussed pre-discharge. This allows for further questions to be answered and reinforces the written information you have given.
- ◆ Discharge the patient in the presence of the parent/carers so they have a clear understanding of the post-operative information and instruction.
- ◆ Introduce an out-of-hours telephone help-line. Many units provide this by having a mobile telephone available that is held by a senior on-call member of the day surgery staff. For all calls, the advice given and the outcome is documented by the person taking the call. A standard proforma can be developed which can be used to audit the service.

Explore the possibility of introducing a day surgery liaison nurse. This role could be undertaken by a nurse from the day surgery unit, or by a number of dedicated day surgery district nurses or a community children's nursing team.

The effectiveness of any pre-admission programme should be regularly audited to ensure the needs of patients, parents/carers are being met. It is worth undertaking a small-scale audit of any parent/carers concerns.

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Further reading

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March 2001

Revised December 2004

Published by the
Royal College of Nursing
20 Cavendish Square
London
W1G 0RN

Tel: [REDACTED]

www.rcn.org.uk

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advice for RCN members.

Publication code 001 375