

PRACTICE OBSERVED

*Practice Research***Paediatric oncology information pack for general practitioners**

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Abstract

An information pack covering important aspects of paediatric oncology has been developed for general practitioners. Sixty general practitioners who received the information pack found that it helped them in managing children with neoplastic disease and their families. The pack has also improved communications between the oncology unit and general practitioners. Similar packs could be produced by paediatricians working in other specialties.

Introduction

Managing children with neoplastic disease presents a difficult challenge for general practitioners who are likely to see only one or two cases of childhood cancer in their career.¹ Though a childhood malignancy affects the whole family, contact between the affected family and the general practitioner is often reduced. This is an inevitable consequence of the highly specialised management, much of which takes place at regional oncology units. Families become increasingly dependent on such units and the general practitioner's day to day participation is often diminished. Confidence in the general practitioner may have been damaged, particularly if there seemed to be a delay in making the diagnosis. Parents soon become familiar with complex details of cancer management, and it often becomes apparent to them that they have

Content of the information package

- Letter of introduction: diagnosis and general prognosis
- Organisation of the oncology unit: direct contact with staff encouraged; telephone and bleep numbers of staff provided
- Appropriate treatment protocol
- Side effects of cytotoxic drugs
- Side effects of radiotherapy
- Infections: management of neutropenic fever; immunisation policy; management of chickenpox and measles contacts
- Management of pain and emesis

a better knowledge than their own general practitioner. Despite the steadily improving prognosis for most childhood cancers, a third of all such patients will need terminal care, which should ideally be given at home and include the general practitioner. Furthermore, the death should be followed by bereavement counselling for the family over a period of months or even years. It is unsatisfactory for the general practitioner to enter the scene only when terminal care becomes necessary.

From the outset we have attempted to include the general practitioner in our family care management by supplying an information pack (see box). The package consists of 12 sheets of A4 paper and is posted to the general practitioner as soon as the condition is confirmed. The pack sets out the diagnosis and explains the organisation of the oncology unit. It gives the appropriate treatment protocol and details of side effects of drugs, and includes a section on radiotherapy. The pack outlines the unit's management

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of common anticipated problems such as fever and neutropenia, chickenpox, and measles. We emphasise the team approach of hospital doctors, nurses, social workers, and the general practitioner; telephone communications are encouraged. We have asked for feedback on the usefulness of this initiative from general practitioners in the South Western region. Their replies are reviewed in this report.

Method

The information packs were sent to 79 general practitioners whose patients presented with cancer or leukaemia over an 18 month period from April 1984 to November 1985. In December 1985 they were sent a questionnaire asking for specific comments on each section. In addition, they were invited to suggest improvements or additions to the pack and to the regional paediatric oncology service in general.

Results

Sixty (76%) general practitioners completed the questionnaire. Seventeen (28%) had received confirmation of the diagnosis within 24 hours of referral; the average time from referral to learning the diagnosis was five days. Fifty nine general practitioners said that they had read the information; 37 said that their partners had read it; 28 had shown it to their health visitor, and 27 to their district nurse. Two thirds of the general practitioners had been telephoned with the results, whereas seven (12%) had not known the diagnosis until they received a discharge summary. Most of them found all the sections of the pack helpful; many requested the addition of a handout on terminal care. Several suggested monthly or three monthly updates on the child's progress rather than routine outpatient letters.

Discussion

Although treatment of childhood cancer must necessarily be carried out primarily in a hospital setting, the impact of a child's

cancer on the family is far reaching and much supportive work can be carried out in the home. General practitioners and primary health care workers are in an ideal position to help the family. With increasing emphasis on home care, particularly when terminal care is necessary,²⁻⁴ it is important that general practitioners should know about managing patients with cancer. Parents are increasingly knowledgeable and expect informed advice from their general practitioner. It was for this reason that the information pack was developed. Most general practitioners found it helpful; the extra information made it easier to work with afflicted families. It was encouraging that the majority showed the pack to other members of the primary health care team—for example, health visitors and district nurses—all of whom are likely to come into contact with the family at home. We are now preparing a sheet on managing terminal care.

An unanticipated bonus from the preparation of the information pack and subsequent feedback from the general practitioners has been the degree to which members of the oncology unit have been made aware of the problems encountered by the general practitioners.

The package gives general practitioners a better chance to maintain contact and credibility with affected families. Those working in other paediatric specialties, especially those whose patients are referred from further afield, may find it helpful to develop information packs to help individual families and general practitioners.

References

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ONE HUNDRED YEARS AGO

Sir Henry Thompson may be justly regarded as the pioneer of the movement in this country in favour of cremation as a means of disposing of the dead without subsequent injury to the living. The famous paper in which he discussed the subject in 1874 in the *Contemporary Review* awoke active discussion, and created a considerable force of public opinion in favour of urn-burial. This ancient procedure, old enough to be a novelty in our civilisation, has had to encounter many prejudices, and all that opposition which arose from centuries of habitual use of inhumation. The controversy which arose out of Sir Henry Thompson's paper did not, however, end in mere words. Simultaneously with the practical efforts to bring cremation to experimental test in other countries, a small Society was established here, of which Sir Henry Thompson, Sir T. Spencer Wells, and Mr. Ernest Hart, were the medical members of Council. This Society, known as the Cremation Society of England, took the necessary steps for erecting a crematorium at Woking, under the direction of Mr. Eassie, CE. It has its offices at 11, Argyll Street, W. It has ever since quietly pursued its way without attempting to force the growth of public opinion, and contents itself with offering to those who desire it the means of cremation, conducted under strict precautions and in an effective and innoxious manner. Writing in the *Nineteenth Century*, which is now edited by the gentleman who originally conducted the *Contemporary Review*, Sir Henry Thompson reviews the progress made, and combats some of the objections which have been urged to cremation, while urging anew the arguments in its favour. He explains the state of the law, which, as laid down by Sir Fitzjames Stephen, permits cremation, and contrasts it with the earlier dicta of Sir Richard Cross when Secretary of State, who formally announced to the Cremation Society that he would oppose their proceedings. Sir Henry Thompson points out that the existing state of the law in respect to cremation does not sufficiently provide for the public safety, and he describes the careful provisions by which his Society fences round the performance of urn-burial with a view to obviate the medico-legal objections which have more than once been urged against cremation as a possible means of concealing crime.

Sir Spencer Wells and Mr. Frederic Harrison have so recently preceded Sir Henry Thompson in their reiteration of the arguments in favour of cremation from the point of view of public health and social convenience, that we need not here recapitulate Sir Henry Thompson's logical, vigorous, and effective pleading under these heads. His paper should be read from beginning to end by everyone who wishes to know all that can be said in favour of cremation and how the objections sometimes urged against it can be adequately met.

The crematorium at Woking is in effective operation, and during the past year sixteen cremations have taken place there. Cremation is effected at a small cost, and under rigorous restrictions as to certificates and *post-mortem* examinations, far more effective than those which are at present applied to ordinary interment. It would be premature to attempt to predict what the future of this mode of disposal of the dead may be in this country; but it is certain that the theological and juridical objections which have been urged against it have to a large extent melted away in face of the practical and carefully measured proceedings of the Cremation Society.

It has, within a short space of time, established itself as a reasonable, practical, and healthy method of disposal of the dead which is compatible with the deepest religious sentiment, and which is capable of being brought within all the requirements of public safety. It is a great thing to have effected so much in so brief a space of time in favour of a procedure which at the outset was met by a violent storm of opposition, and which was alleged to outrage public sentiment. Bishops and archbishops, statesmen, philosophers, and sanitarians representative of most influential bodies, have pronounced in favour of it. The energy and public spirit of a small number of persons have placed at the disposal of the public the means of giving effect to any opinion which exists in favour of cremation, and there can be no doubt that the present essay by Sir Henry Thompson will do much to forward the further growth of a movement which has already made great progress.

(*British Medical Journal* 1888;i:28)