

PRECIOUS TIMES

A handbook on palliative care for parents of children with cancer

This handbook was first published in 2000 and re-edited in 2004 by the team of Clinical Nurse Specialist's and Social Worker's in the Haematology/Oncology unit at Our Lady's Hospital for Children, Crumlin. Much has been documented about the importance of giving families written information to support what they have been told when their child has been diagnosed with cancer. It had been felt for some time that while parents were given lots of written information regarding diagnosis, and treatment during the 'active' phase, there was a need to give them information about the palliative phase of their child's illness that they could go through at their own pace.

As at the time of diagnosis, shock and distress can often hamper what families are able to hear and understand when 'bad news' is being given. For many parents this is the worst time of all, when their hopes for cure are being taken away from them. Their first instinct is often to want to leave the hospital as quickly as possible, and the staff involved may feel that it's not appropriate to begin talking about the expected course of events at that time. With this in mind, the handbook was written to give support and information to families which will hopefully help them during this difficult time.



It contains practical information about the people who are involved in the care of these children in the community, some of the symptoms that may arise, information about children's understanding of death, communicating with siblings, planning funerals etc. It also deals with some questions that parents are afraid to put into words, as the reality is all too painful for them. The book is divided clearly into different sections, to allow families to 'dip' in or out as they wish.

Abstract taken from the introduction

The purpose of this book is to give you and your family information, which will hopefully help you during this difficult time of palliative care. It is hoped that the book will reduce some of the desperation that you might now be feeling on hearing that there is no further active medical treatment for your child's disease. It is a book for parents written with the help of families who have experienced some of what you may now be going through. These parents suggested the title "Precious Times".

The term Palliative Care is used to describe supportive care and treatment that is given to alleviate symptoms, but with the knowledge that it will not lead to a cure. Palliative care means that your child's comfort and dignity become the priority. Most of this care is given at home.

The progression of your child's disease to this end stage may have come as a total shock to you, or you may have been the one to identify it. Either way, the past few days have probably been the worst ever. At this moment you are most likely feeling shocked and devastated. Your abilities and strengths as a parent will hopefully be supported by us and by

this book. Questions may arise in your mind, seeming almost too terrible to ask, therefore some of these will be addressed gently in this text.

It can be difficult to put some issues that are sensitive on paper. So the book is divided clearly into different sections, for your convenience. It may be that you will only be able to read some sections of this book at present. You may not be quite ready for it all yet, thus your Clinical Nurse Specialist and Social Worker are available to discuss any of the issues with you when you feel the time is right.

Your child is very important to us. We hope this book and our service will be of some help.



Precious Times is the winner of the European Oncology Nursing Society's

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The Precious Times booklet can be obtained from the Irish Cancer Society's Cancer Information Service on 1800 200 700 or by email: helpline@irishcancer.ie