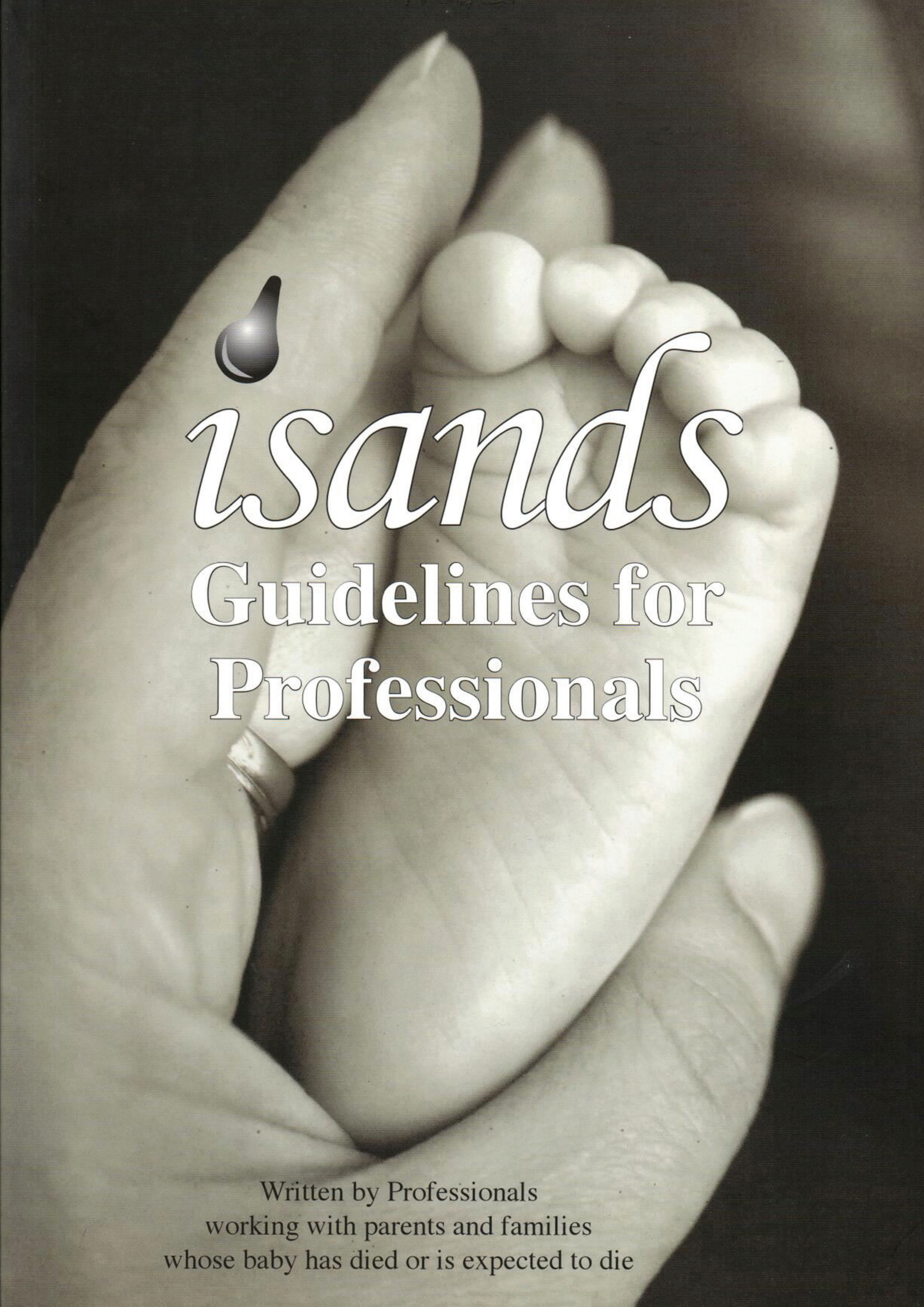

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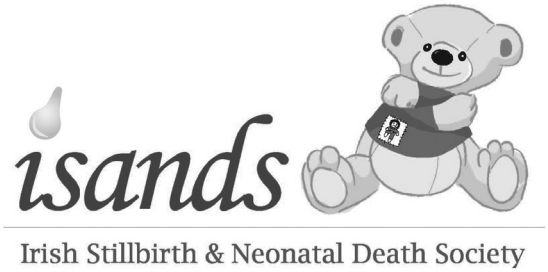
Guidelines for Professionals

Written by Professionals
working with parents and families
whose baby has died or is expected to die



GUIDELINES FOR PROFESSIONALS

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ISANDS 2007

Acknowledgments

ISANDS would like to thank all the Professionals who contributed to this publication both within the Hospital environment and outside in the Community. We are grateful to them for sharing their advice, suggestions and compassionate insight. We would also like to thank all the bereaved parents whose contribution provided an important and valuable content to this book. A list of all those who contributed to this publication are at the back of this book. Neither ISANDS nor any of the Authors shall not be responsible or liable for any loss, damage, liability or claims (whether direct or indirect) that arise or out of or in connection with the Guidelines.

We acknowledge the assistance of the VHI Staff Support towards funding the printing of these 'Guidelines for Professionals.

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The ISANDS Guidelines for Professionals are offered as a suggestion for good practice and is the first collation of findings of studies, experience, and feedback from various contributors. It has taken considerable time to bring the project to fruition and ISANDS would consider it work in progress, which in time will develop with further changes, hospital policy and legislation governing standards and practices.

Foreword

It is an honour for me to have the opportunity to write the foreword for this very important publication. Since its establishment in 1983, the Irish Stillbirth and Neonatal Death Society has helped us all to recognise that the intense pain and grief associated with losing a baby is best supported in a range of ways.

The support of everyone connected with the family can be of huge benefit to the bereaved in dealing with their loss, but it is often difficult for people to understand how to express their support in practical ways. This publication is designed to help everyone, from health professionals to funeral directors, from teachers to employers, to deal with the many issues which arise following the death of a baby in a sensitive and caring way and to support parents and other relatives to cope with what is one of life's most difficult experiences.

Importantly, the publication points out that not all bereaved families are the same, and what is acceptable to one may not be acceptable to others. What matters is that people are aware of the issues and the choices that are available so that the families can decide what is appropriate for them.

Finally, I would like to pay tribute to those people who have contributed to these guidelines, and particularly to the bereaved parents who shared valuable insight to help to make a difference to parents and families in the future.

Mary Harney, T.D.
Minister for Health and Children

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**This Book is divided into sections under relevant professions.
It is designed to give you easy access to the relevant information
at a time needed without having to read a whole book
Some information and suggestions are repeated in several sections
as they are appropriate to be included.
We have mentioned other relevant sections that might be useful
at the end of each section.**

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Introduction

These Guidelines are the result of ten years work with various groups of professionals and individuals. They combine views, good practice and discussions based on research and experiences of many professionals within the Hospital environment, the Community and important feedback from bereaved parents and families and parent led groups.

The changes that have come about in this area of care in the last twenty years are considerable. Parent groups like ISANDS have played a significant role in bringing about some of the changes. Many Health Care Professionals also played an exemplary role in providing insightful compassionate care to parents and their families at a time of great sadness and loss. We acknowledge their pioneering approach and understanding, which has given us the opportunity and climate to develop new practices and skills.

One of the most fundamental elements of this area of care apart from resources is the time factor involved. Allocating time, at the pace that is necessary, to attend in a sensitive way to the needs of parents presented with a traumatic situation is difficult, especially in an already over burdened service which is generally understaffed. However, TIME may be one of the key factors to managing sensitive care for parents and in the long term it may take parents out of other general health care service or specifically out of psychiatric and counselling services. In a world of complaints, litigation and unfavourable publicity, some of the above may be a better option.

Many of the recommendations suggested in the book are similar to recommendations for law reform currently under development or amendment.

These Guidelines provide a point of reference for professionals based on studies and experiences across the board but it is also necessary to be aware that some of the suggestions and recommendations may still be unacceptable to some parents and their families. It is always better practice to give choices and find out what is appropriate for them.

The Guidelines are a stepping-stone in some areas of uncharted waters and we hope they will be useful to bring about or direct changes. We see this publication as a work in progress and fundamental to it being used as a valuable and successful reference source, is the need to update and continue to develop information within. In order to do that most productively it is necessary for ISANDS to continue to work with health care professionals and other individuals.

The development through communications between professionals themselves and with parents and parent groups will be enhanced through open exchange. Feedback from those working in this area of care and those using this publication will continue to be invaluable in developing the content as a valuable resource.

Our thanks to all the Health Care Professionals, other individuals, parents and families who have contributed to this pioneering publication. It has been a privilege to work with everyone involved. A list of all those who worked on the project, contributed comments and suggestions is written at the back of the book.

Ron Smith-Murphy, National Chairperson, ISANDS
and Members of the National Executive of ISANDS (2007)

What we call the beginning
is often the end.
And to make our ends
is to make a beginning.
The end is where we start from.

T.S. Eliot