

A SUPPORT PACK FOR HEALTH PROFESSIONALS

**Working with
families affected
by a disability
or health condition**
from pregnancy
to pre-school

cntact a family
for families with disabled children

This resource is intended for all health professionals working with families of disabled children including ultrasonographers, obstetricians, midwives, neonatologists, neonatal nurses, paediatricians, health visitors, specialist nurses, therapists and counsellors.

“Its aim is to highlight parents’ needs for accessible information and appropriate support at significant times from pregnancy to pre-school.”

Examples of the events covered include:

- prenatal diagnosis
- death in utero
- a stay on a neonatal unit
- referral to a genetics clinic

This pack has been informed by the knowledge, experience and views of health professionals, parents and professionals within the voluntary sector.

Contact a Family is a UK charity providing support and advice to families with disabled children and children with specific health conditions.

Contact a Family offers:

- Access to expert advisers via a dedicated national freephone helpline.
- Regularly reviewed, authored and dated information on over 1000 rare disorders through the Contact a Family Directory of Specific Conditions, Rare Disorders and UK Family Support Groups including health information and groups supporting families. <http://www.cafamily.org.uk/home.html>
- A wealth of practical information on-line at Contact a Family’s award-winning website.

Contact a Family has offices in Scotland, Northern Ireland and Wales and a network of regional offices and London projects. These offer a range of services including family support, workshops and local information. Contact a Family also has a network of local volunteer representatives who are all parents of disabled children. They offer information and support to families. Further details of what is available in your own area can be found on the Contact a Family website.

contact a family
for families with disabled children

209-211 City Road, London EC1V 1JN

Helpline: 0808 808 3555

Website: www.cafamily.org.uk

February 2006

<http://www.cafamily.org.uk/HealthSupportPack.pdf>

Contact a Family would like to thank all those who have contributed to this resource.

Written by Lucy Arnold MSc, Information Officer (Rare & Genetic Disorders) and other members of Contact a Family staff.

Contact a Family would like to thank the Department of Health and Department for Education and Skills for assistance in funding this project.



Supported by



department for
education and skills

contents

- 1 PRENATAL DIAGNOSIS
- 2 OPTIONS FOLLOWING A PRENATAL DIAGNOSIS
- 3 DEATH IN UTERO
- 4 INFORMATION SHARING IN NEONATAL UNITS
- 5 CARE AND SUPPORT AT HOME – the role of the health visitor
- 6 HOSPITAL CARE – the role of the health visitor
- 7 REFERRAL TO A GENETICS CLINIC
- 8 SUPPORT FOR FATHERS, SIBLINGS, GRANDPARENTS
- 9 GOOD PRACTICE IN SHARING NEWS
- 10 CONTACT A FAMILY AND OTHER SOURCES OF INFORMATION
- 11 EARLY SUPPORT – Supporting co-ordinated services (only applicable in England)

Introduction

Every day over 95 women are told there is a risk that their unborn baby will have a serious abnormality. Every day over 75 children are born or diagnosed with a disability or health condition. In these situations, parents need ongoing information and support, often before a diagnosis is reached.

Having a child with a disability or serious health condition has an impact well beyond diagnosis, prognosis and subsequent health treatment. There are wider social implications for the family and child.

Sharing news with parents about a child is a challenging task requiring skill and sensitivity. This is likely to be one of the most significant pieces of information parents ever receive. Their experience at this time is likely to have a huge impact upon them and their child's future.

This multidisciplinary resource is written primarily for health professionals working with children including ultrasonographers, obstetricians, midwives, neonatologists, neonatal nurses, paediatricians, health visitors, specialist nurses, therapists and counsellors. Its aim is to highlight parents' needs for accessible information and appropriate support when receiving news about a disability or health condition, from pregnancy to pre-school years. All information is based on consultation with parents, voluntary sector organisations and health professionals and on current guidelines for good practice.

Language is used, particularly medical terms, with parents and potential parents in mind. The word 'parents' is used throughout for convenience. We recognise that there are many women without a partner, or whose partner is not their child's father and, occasionally, some men without a partner. We also appreciate that some primary carers will not consider themselves parents.

Contact a Family provides support, advice and information for families with disabled children. In April 2004 Contact a Family embarked upon a three year project with the **Royal College of Paediatrics and Child Health**. Working directly with paediatricians and other health professionals, the project aims to improve the information given to parents at the time of diagnosis and on an ongoing basis and to ensure that families are put in touch with Contact a Family and other support organisations. We hope this pack will be a useful resource within this context.

A Welsh version of this support pack is available – see <http://www.cafamily.org.uk/wales/index.html>

Contact a Family has a range of posters, factsheets and helpline cards for use within your clinic or ward, including information on tape, in Welsh and in other languages. Our freephone helpline offers support to parents and information to professionals. Please do call us if you need any information.

Helpline: 0808 808 3555

Monday to Friday 10am-4pm, Mon 5.30-7.30pm

Textphone: 0808 808 3556

Prenatal diagnosis

This information sheet is intended for all health professionals meeting parents at or around the time of a prenatal diagnosis.

The moment an anomaly is identified or suspected on a scan

For most parents, a detailed scan is a positive experience that offers reassurance as well as the chance for a photograph of their baby. Most parents come for a routine scan assuming that everything is 'normal' and are shocked by, and unprepared for, news of an anomaly or diagnosis. Only a few parents coming for a scan are prepared for the 'worst', though perhaps hoping for the 'best'. Parents usually realise when something on a scan is causing concern. Changes in the health professional's behaviour and body language, such as leaving the room without an explanation, or an unexplained silence, may give clues.

Key points

- Find out what pre-scan information and support your unit offers. Do parents give informed consent? Do parents know the purpose and limitations of the procedure? Do parents know what communication to expect during the scan? Explaining this information at the outset may allay some parents' anxiety, particularly from silences.
- Inform parents as and when factors, such as the positioning of the unborn, make scanning difficult.
- Acknowledge the limitations of your role. If you need to get a second opinion, saying something like, *'I'd like to get a colleague to have a closer look at ...'* helps parents feel included.
- Recognise the impact of information obtained from a scan. A sentence such as *'I understand this must have come as a great shock'* may help parents feel cared for.
- Make the place 'private' and more appropriate – close the door and have a proper conversation with the parents.
- Parents may respond differently to the situation. Tailor information and support to respective need.
- Offer contact details of a lead health professional whom parents can contact during the pregnancy and/or the morning after the scan. Refer their case to the lead health professional.
- Document all relevant information in the hand-held notes, care plan and hospital notes.
- Establish clear guidelines on the communication process from consultant through to clerical staff.

- Establish efficient communication between local and specialist units.
- Establish efficient communication between local staff, the hospital and community staff.

Referral for confirmation and/or further information

The amount of information parents initially receive may vary. It can range from being told there is a problem, with no further detail, through to complete, detailed information. If ultrasound findings cannot be clearly or easily confirmed, parents may feel anxious; subsequent findings may leave them feeling they are on an emotional 'roller coaster'.

Key points

- Ask parents to give the name of their lead health professional; also ask whom they see as their main point of contact. Pass all information on to this professional.
- Provide full and accurate information about invasive tests for chromosome analysis.

Sharing news with parents

Although parents are always distressed to find out that something may be 'wrong' with their unborn baby, emotional responses may vary considerably. It is important to recognise that the way parents are given information can have a long-lasting positive or negative impact on their decisions and experiences.

When hearing news, parents often hear messages different from those intended.

- Bear in mind that, for some parents, the clinical picture can sound like a list of 'what the unborn baby won't be able to do' without referring to 'what the unborn baby will be able to do'. Parents may be minimising or maximising what they are hearing. Their perception of 'disability' and severity may also be genuinely different from yours.
- For some parents, it can seem as though the unborn baby is being described as an 'interesting medical case', particularly if they are aware of a number of observers in the room.

- Parents who are referred to a number of professionals, including obstetricians, neonatologists, paediatric surgeons and geneticists can feel they are given differing accounts of prognosis.

Key points

- When available, communicate full and accurate information in understandable, non-medical terms. Be aware that medical terms can convey to parents that this is a purely medical experience rather than also a very human and emotional one.
- When full and accurate information is not available, explain any uncertainties in the diagnosis and prognosis. Explain that it is often not possible to predict likely long-term outcome with any degree of certainty.
- Check parents' understanding of the information given.
- Recognise that parents may have different needs for information and that they are likely to vary in their emotional responses.
- Offer time for reflection and an opportunity to ask questions, however 'trivial' these may seem.
- Identify whether parents want to know the sex before describing the unborn as 'he' or 'she'.
- Ask if a family member who is not present would like an appointment or telephone call for an explanation.
- Ensure that cultural differences are fully supported – offer interpreters or health advocates where necessary, as well as relevant translated literature, where possible. Further information is available from Language Line (see [Useful organisations](#)).
- Offer parents an agreed time alone; give them the space they might appreciate.
- Offer a referral to the relevant clinician, specialist nurse, midwife or health visitor as appropriate. Document your discussion in the notes.
- Offer assistance in formulating relevant questions for other health professionals.
- Find out if and when parents would like up-to-date written information on the condition, support group and local services. If requested, document the resources given.

Health professionals' needs

- Knowledge of the unit's policy on training and the professional's own training needs, particularly around communication skills, sharing news and disability equality.
- Knowledge of the communication policy and any local guidelines on talking to parents within the local hospital trust.
- Knowledge of the formal and informal support mechanisms in place and an opportunity to ask for support if needed.

Useful organisations

ARC (Antenatal Results and Choices)

73–75 Charlotte Street, London W1T 4PN
 Helpline: 020 7631 0285 (10am–5.30pm, Mon–Fri)
 Tel/Fax: 020 7631 0280
 e-mail: info@arc-uk.org Web: www.arc-uk.org

BDF Newlife (Birth Defects Foundation)

BDF Centre, Hemlock Business Park, Hemlock Way, Cannock, Staffordshire WS11 7GF
 Helpline: 08700 707020 (9.30am–5.00pm, Mon–Fri)
 Tel: 01543 468888 Fax: 01543 505989
 e-mail: help@bdfnewlife.co.uk Web: www.bdfcharity.co.uk

Contact a Family

209–211 City Road, London EC1V 1JN
 Freephone Helpline: 0808 808 3555 (10am–4pm Mon-Fri, & Mon 5.30pm-7.30pm)
 Fax: 020 7608 8701 Textphone: 0808 808 3556
 e-mail: info@cafamilly.org.uk Web: www.cafamilly.org.uk

Genetic Interest Group (GIG)

Unit 4D, Leroy House, 436 Essex Road, London N1 3QP
 Tel: 020 7704 3141 Fax: 020 7359 1447
 e-mail: post@gig.org.uk Web: www.gig.org.uk

Language Line Limited

11–21 Northdown Street, London N1 9BN
 Tel: 020 7520 1430 Fax: 020 7520 1450
 e-mail: enquiries@languageline.co.uk
 Web: www.languageline.co.uk

Useful resources

Abramsky L, Chapple J (editors) (2003) *Prenatal Diagnosis – The Human Side*, 2nd edn. Nelson Thornes.

Boyle RJ, de Crespigny L, Savulescu J (2003) An ethical approach to giving couples information about their fetus. *Human Reproduction* **18** (11): 2253–6.

Kaplan D (1994) Prenatal Screening & Diagnosis: The Impact on Persons with Disabilities. In KH Rothenberg and EJ Thomson, editors. *Women & Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus: Ohio State University Press.

Royal College of Obstetricians & Gynaecologists and the Royal College of Paediatrics & Child Health (1997) *Fetal Abnormalities Guidelines for Screening, Diagnosis and Management. Report of the Joint Working Party of the Royal of Obstetricians & Gynaecologists and the Royal College of Paediatrics & Child Health*. London: RCOG & RCPCH.

Statham H, Solomou W, Green JM (2001) *When a baby has an abnormality (volume 1): a study of parents' experiences*. Centre for Family Research, University of Cambridge, Cambridge.

The Contact a Family Directory, Specific Conditions, Rare Disorders and UK Family Support Groups, annual edn. Contact a Family.

Options following a prenatal diagnosis

This information sheet is intended for all health professionals meeting parents after a prenatal diagnosis.

The decision-making process following a prenatal diagnosis

Confirmation of a diagnosis or an anomaly can lead parents to one of the most difficult decisions they have ever faced – whether or not to continue with their pregnancy. Factors influencing decision-making may include the seriousness of the condition, the future possibility of the unborn child leading an independent life, the impact of the condition on the rest of the family, and the parents' attitudes towards disability and termination. Other factors may include the unborn's chances of survival and the predicted quality of life after surgery. Moral, religious and cultural beliefs may also inform parents' decision-making. Parents may find it particularly difficult to make a decision where prognosis and severity are uncertain, or if new findings become apparent later in the pregnancy.

Key points

- Offer as full and accurate information as you can about all options, including services after birth.
- Check parents understand the options.
- Be aware that different parents want varying amounts of information and in different formats.
- Explain whether or not there is a time pressure. Be clear about what the time pressure is and why it exists.
- Ensure that cultural differences are fully supported – offer interpreters or health advocates where necessary, as well as translated literature, where possible. Further information is available from Language Line (see [Useful organisations](#)).
- Give parents time to reflect upon and ask questions.
- Many parents ask *'What would you do in my place?'* Parents can feel abandoned and unsupported if your reply (to the effect of 'this is not my choice') is phrased in an unqualified way. Recognise your own ethical and moral position and support the parents in whatever choice they make.
- Give parents time to make a decision and recognise how difficult this is under time pressure.
- Make sure that parents are offered support, respect and information in a way that will allow them to live with their decision for the rest of their lives.
- Offer a referral to other professionals including a

neonatologist, paediatric surgeon and geneticist, as appropriate (see [Information sharing on neonatal units Information Sheet 4](#)).

- Offer assistance formulating relevant questions for respective health professionals.
- Ask if, and when, parents would like information on voluntary organisations, for example, ARC (Antenatal Results & Choices) or Contact a Family (see [Useful organisations](#)).

Termination of pregnancy

Whatever the reason for the termination, and whatever stage of pregnancy this takes place, parents need information about what is involved. Some parents will request more detailed information than others – it is important, therefore, to sensitively identify and meet respective need.

Key points

- Use plain English at all times – jargon may confuse parents. Medical terms can also convey to parents that this is a purely medical experience rather than also a human and emotional one.
- Offer information on how and where the termination will be carried out.
- Offer information on whether or not it will be possible to see the baby's body.
- Give honest and thoughtful responses to questions such as, *'Will the baby feel any pain?'*, *'What will the baby look like?'*, *'Will I be able to say goodbye?'*
- Feel prepared to discuss the short and long-term psychological effects of terminating a pregnancy.
- Give parents an opportunity to discuss their feelings with a support nurse or midwife, both before and after the termination.
- Refer for counselling before and after the termination, if appropriate. Offer details of in-house bereavement support, hospital chaplain, GP counsellor, and voluntary sector organisations. Ensure contact details are documented somewhere other than maternity/hospital records.
- Ask if and when parents would like to be offered the ARC Handbook (see [Useful resources](#)).
- Offer information on the post-mortem and what will happen to the baby's body. Discuss the importance of obtaining a correct diagnosis for estimating the risk to further pregnancies. Sensitively let parents know that the most reliable basis for a genetic diagnosis is a post-

mortem. However, if parents do not want a post-mortem, detailed photographs, X-rays or tissue samples for chromosome analysis might also be useful. Inform parents that a post-mortem may not provide a diagnosis.

- Establish efficient communication between local staff, hospital and community staff.

Continuing with the pregnancy

For many parents who continue with their pregnancy, it can seem like the main focus is the pregnancy.

Key points

- Recognise parents' feelings. They may be ambivalent – looking forward to their baby's birth but also anxious and concerned. Parents may carry a sense of guilt and failure. They may also feel responsible for letting the baby down in some way. Be aware that these feelings sometimes translate as anger towards health professionals.
- Feel prepared to discuss the short and long-term psychological effects of continuing with a pregnancy.
- Encourage parents to meet a (named) midwife in the delivery suite and make a birth plan.
- Encourage parents to visit the neonatal unit and discuss where the birth will take place (see *Information sharing on neonatal units Information Sheet 4*).
- Offer help in formulating questions for relevant health professionals.
- Ask if and when parents would like relevant written information on the condition, details of condition-specific support groups and ARC publication (see *Useful resources*).
- Offer details of professionals with whom parents can discuss their feelings after birth including midwives, health visitors, in-house bereavement counsellors, genetic counsellors, hospital chaplains and voluntary sector organisations (see *Useful organisations*).
- Offer information on subsequent short and long-term treatment for the baby and services from the multidisciplinary team available.
- If it is known that the baby will die at or shortly after birth, sensitively offer parents information about a post-mortem. Offer the opportunity to discuss the examination with a professional best qualified to respond to their questions.
- Offer details of the lead health professional whom parents can contact during the pregnancy.
- Establish efficient communication between local staff, the hospital and community staff.

Health professionals' needs

- Knowledge of the unit's policy on training and the professional's own training needs, particularly around communication skills, sharing news and disability equality.
- Knowledge of the communication policy and any local guidelines on talking to parents within the local hospital trust.
- Knowledge of the formal and informal support mechanisms in place and an opportunity to ask for support if needed.

Useful organisations

ARC (Antenatal Results and Choices)

73–75 Charlotte Street, London W1T 4PN
 Helpline: 020 7631 0285 (10am–5.30pm, Mon–Fri, Mon 5.30–7.30pm)
 Tel/Fax: 020 7631 0280
 e-mail: info@arc-uk.org Web: www.arc-uk.org

Contact a Family

209–211 City Road, London EC1V 1JN
 Freephone Helpline: 0808 808 3555 (10am–4pm, Mon–Fri, Mon 5.30–7.30pm)
 Fax: 020 7608 8701 Textphone: 0808 808 3556
 e-mail: info@cafamily.org.uk Web: www.cafamily.org.uk

Language Line Limited

11–21 Northdown Street, London N1 9BN
 Tel: 020 7520 1430 Fax: 020 7520 1450
 e-mail: enquiries@languageline.co.uk
 Web: www.languageline.co.uk

Useful resources

ARC (Antenatal Results and Choices) (1999) *Parents Handbook: a handbook to be given to parents when their unborn baby is diagnosed with an abnormality.* www.arc-uk.org

ARC (Antenatal Results and Choices) (2003) *Supporting You Throughout Your Pregnancy: a handbook for parents after a prenatal diagnosis.* www.arc-uk.org/cap.htm

Royal College of Obstetricians & Gynaecologists and the Royal College of Paediatrics & Child Health (1997). *Fetal Abnormalities Guidelines for Screening, Diagnosis and Management. Report of the Joint Working Party of the Royal College of Obstetricians & Gynaecologists and the Royal College of Paediatrics & Child Health.* London: RCOG & RCPCH.

Statham H, Solomou W, Green JM (2001) *When a baby has an abnormality (volume 1): A study of parents' experiences.* Centre for Family Research, University of Cambridge, Cambridge.

Statham H (2002) Prenatal diagnosis of fetal abnormality: the decision to terminate the pregnancy and the psychological consequences. *Fetal and Maternal Medicine Review* **13**: 213–247.

The Contact a Family Directory, Specific Conditions, Rare Disorders and UK Family Support Groups, annual edn. Contact a Family.

Death in utero

This information sheet is intended for all health professionals meeting parents at the time of an in utero death.

The moment an in utero death is confirmed

A strong bond may already exist between parents and the unborn baby. As such, parents may be acutely fearful of the possibility that there is cause for concern.

Key points

- Ensure that parents are not left alone for long periods or made to wait in public places within the clinic/hospital.
- In the case of only one parent being present, ensure that she is given the option of contacting her partner, a relative or friend. Recognise, however, that some women actually prefer to be alone.
- At the time of death, many parents value a personal expression of sympathy from their health professional.
- Offer parents respect, privacy and emotional space at this time.
- Be aware that the father's response may differ considerably from that of the mother.
- Offer parents the SANDS (Stillbirth and Neonatal Death Society) helpline contact details (see [Useful organisations](#)).
- Inform the GP and community midwife.

Preparation for induction and labour

The prospect of giving birth to a dead baby can be very frightening. Parents may have assumed they would have a Caesarean section and may need time to come to terms with the idea of a vaginal birth. The experience of labour is a very significant one. For many parents, birth represents the breaking of the physical bond – this may be when they fully realise their baby is dead. It is also one of the last times parents are able to be with their baby.

Key points

- Communicate full and accurate information in understandable, non-medical terms about forthcoming events, decisions and procedures. Medical terms may convey to parents that this is a purely medical experience rather than also a human and emotional one.
- When full and accurate information is not possible, explain any uncertainty.

- Offer to repeat information. Remember, grief and shock can affect the parents' ability to retain information and make sense of what is happening.
- Recognise that the father's needs for information, support and involvement may differ from those of the mother.
- Ensure that cultural differences are fully supported – offer interpreters or health advocates where necessary, as well as relevant translated literature, where possible. Further information is available from Language Line (see [Useful organisations](#)).
- Allow parents adequate time to consider the options available, acknowledging that distress can affect their ability to make a decision.
- Where possible, offer parents a choice about when the induction can take place. Recognise that some parents will want to deliver as soon as possible, whilst others will need more time.
- If parents are going home before induction, offer contact details of a lead health professional whom they may contact. Also offer the SANDS helpline number (see [Useful organisations](#)).
- Welcome and encourage questions, particularly questions that parents need to ask but find difficult to express.
- Parents may be anxious about what their baby will look like. Explain this gently.
- Offer support as you prepare parents for the physical appearance of the baby, especially for a twin pregnancy where one has died before the birth of the survivor.

After delivery

The time that parents spend with their baby after he or she is born is very precious. It forms the basis of treasured memories for the future. It is important for parents to spend as much time as they need with their baby and choose what they want to do at this time.

Key points

- Offer parents a private room (if this available) and physical distance from live babies.
- Ensure parents are aware of their choices, for example, holding their baby, washing and dressing the baby, taking photographs. Be aware that parents may choose to bring their own clothes or toys for the baby.
- If parents want to take photographs, gently inform them that the photographs should be good quality – Polaroid photographs can fade with time.

- Recognise the importance of physical reminders of the baby. Often parents value a memory card to collect hand and footprints.
- Welcome other family members.
- Show sensitivity to differences in religious and cultural beliefs and rituals.
- If appropriate, offer support from a member within the team, member of the hospital chaplaincy team or from parents' own spiritual leader.
- Discuss the importance of a correct diagnosis for estimating the risk to further pregnancies. Sensitively communicate that the most reliable basis for a genetic diagnosis is a post-mortem and that, if the parents do not want to have a post-mortem, tissue samples for chromosome analysis may be useful. Detailed photographs or X-rays might be useful, although these may be more limited in their results. Sensitively explain differences between clinical and personal photographs.
- Offer parents the opportunity to discuss a post-mortem with the professional best qualified to respond to relevant questions.
- Mark notes with a sticker to indicate a perinatal loss.

On discharge

Leaving hospital without a baby is one of the lowest points for many parents. They may be unaware of local support groups or professionals with whom they can discuss their feelings.

Key points

- Ask if and when parents would like contact details of organisations and professionals trained in bereavement support or counselling. These might include in-house bereavement counsellors, hospital chaplains, GP counsellors, registered counselling agencies, local church groups and appropriate voluntary sector organisations (see [Useful organisations](#)).
- Establish an efficient communication system between specialist, local and community staff. The community midwife may provide immediate support when completing a 10 day postnatal check and can offer short-term support. Health visitors may also support parents in the grieving process and around the anniversary of the baby's death.
- Give full information about post-natal bleeding and breast milk production and the name of a key health professional who can be contacted.
- Inform the GP, health visitor, community midwife and other professionals involved in care, thereby preventing dissemination of inappropriate follow-up correspondence.
- Offer information about funeral options and registering a stillbirth. This is available from SANDS (see [Useful organisations](#)).

Health professionals' needs

The death of a baby in utero is a sad event for health professionals and may cause emotional strain within the team.

- Knowledge of the communication policy and any local guidelines on talking to parents within the local hospital trust.
- Knowledge of the unit's policy on training and the professional's own training needs, particularly around communication skills and sharing news.
- Knowledge of their own formal and informal support mechanisms and an opportunity to ask for support if they need it.

Useful organisations

Child Death Helpline

Freephone Helpline: 0800 282986

(10am–1pm Mon, Fri 1pm–4pm Wed 7pm–10pm Mon, Sun)

Web: www.childdeathhelpline.org.uk

Language Line Limited

11–21 Northdown Street, London N1 9BN

Tel: 020 7520 1430 Fax: 020 7520 1450

e-mail: enquiries@languageline.co.uk

Web: www.languageline.co.uk

SANDS (Stillbirth and Neonatal Death Society)

28 Portland Place, London W1B 1LY

Helpline: 020 7436 5881 (10am–4pm, Mon–Fri)

Tel: 020 7436 7940 Fax: 020 7436 3715

e-mail: support@uk-sands.org Web: www.uk-sands.org

Useful resources

Kohner N (1995) *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals*. SANDS.

Kohner N, Henley A (2001) *When a Baby Dies, The experience of late miscarriage, stillbirth and neonatal death*, 2nd edn. Routledge.

Moulder C (1998) *Understanding Pregnancy Loss: Perspectives and Issues in Care*. Macmillan.

The Contact a Family Directory, Specific Conditions, Rare Disorders and UK Family Support Groups, annual edn. Contact a Family.

Thomas J (1993) *Death at Birth*. A two-part training video for professionals. The Child Bereavement Trust, High Wycombe. www.childbereavement.org.uk

Information sharing in neonatal units

This information sheet is intended for all health professionals meeting parents on a neonatal unit.

An antenatal referral

When an anomaly has been identified on a scan, parents are offered an opportunity to discuss the implications with a number of health professionals (see [Options following a prenatal diagnosis Information Sheet 2](#)). Parents may be strongly affected by the different perspectives of prognosis offered by obstetricians, neonatologists and paediatric surgeons, however slight these differences might be.

Key points

- If only one parent is present when you are providing information, ask if she would like to be accompanied by a partner, family member or friend at the hospital.
- Recognise the impact of receiving this information. A phrase such as, *'I appreciate this must have come as a shock to you'* can make all the difference.
- Check parents' knowledge and understanding of diagnosis and prognosis.
- Communicate information as fully and accurately as possible in understandable, non-medical terms. As well as potentially confusing parents, medical terms may convey the idea that this is a purely medical experience rather than also a human one.
- If full and accurate information about diagnosis and prognosis is not possible, explain this.
- Ensure parents are aware that sometimes the outcome is different from expected. It may be appropriate to say something like, *'It is difficult to predict the outcome until the baby is born but it is likely to be...'*
- Give parents an opportunity to ask questions and discuss the results, either at the time, or at a later appointment.
- If the baby is likely to require neonatal care, offer parents an opportunity to visit the neonatal unit prior to delivery.
- Offer parents sufficient time to reflect and make decisions. Make sure that they have time alone to discuss their options.
- Ask if and when parents would like up-to-date written information on the condition and details of relevant support groups.
- Ask if and when parents would like BLISS, the premature baby charity, freephone helpline contact details (see [Useful organisations](#)) and, where possible, BLISS Parent Information Guide (see [Useful resources](#)).

- Offer details of a lead health professional whom parents can contact during the pregnancy. Refer their case to this person.
- Document the agreed plan of care and make this accessible to all healthcare professionals including the GP and primary care team.
- Establish an efficient system of communication between the Fetal Medicine Unit and the Neonatal Unit; by arranging weekly communication meetings to ensure that important care decisions are discussed, for example.

After birth

Health professionals are in a key position to facilitate the relationship between parents and the newborn baby.

Key points

- Encourage parents to have physical contact with their baby.
- Be positive. Comments such as *'Isn't she beautiful...'* or *'How well you hold her...'* can facilitate parents' relationships with their baby.
- Welcome visits from family members.
- Encourage parents to be present at the initial newborn examination.
- Summarise complex discussions in the notes and share with parents.
- Ask if and when parents would like up-to-date medical information on the baby's condition and details of support groups, where appropriate.
- Offer information on parent group meetings, if these are arranged on the unit.
- Liaise with the health visitor or specialist nurse and invite them to the unit prior to discharge.
- Establish efficient communication with the multidisciplinary team and offer written contact details of relevant health professionals.

Going home

- Allow parents time to discuss any anxieties and concerns about taking the baby home, including the impact on the wider family.
- Offer information on the range of health professionals available to assist parents at home.
- Establish efficient communication between the hospital and community health professionals.

Sharing news about a critically ill newborn baby

Although parents may want detailed information about the future, it is often not possible to predict long-term outcomes with any certainty. Health professionals need to be prepared to admit these uncertainties to parents.

Key points

- Before seeing parents, discuss the baby with colleagues and try to reach a consensus on the baby's care plan. A consensus view will be helpful to parents.
- Before seeing parents read the maternal and fetal notes.
- Offer detailed information in understandable, non-medical language including:
 - ▶ diagnosis and explanation of cause
 - ▶ prognosis and degrees of certainty
 - ▶ treatment options where available.
- Refer to the baby by name and demonstrate by your actions and words that you recognise and value the baby as a unique and precious individual.
- Do not be afraid to express your emotions when discussing tragic news with parents. In these circumstances, many parents find it helpful when health professionals show their human involvement.
- Involve parents in making decisions, encourage them to carry out containment holding, kangaroo care, changing nappies, feeding or tube feeding their baby.
- Encourage parents to be involved in their baby's care during his or her time on the neonatal unit.
- Encourage parents to involve siblings.
- Talk to the parents frequently and ensure all information is communicated in an accessible way showing sensitivity to the diversity of parents' circumstances and personal experiences.
- Ensure that cultural differences are fully supported – offer interpreters or health advocates where necessary, as well as relevant translated literature, where possible. Further information is available from Language Line (see [Useful organisations](#)).
- Listen to parents and answer their respective questions as fully and honestly as possible.
- Acknowledge that fathers may have different information and support needs from mothers and may respond differently to the situation.
- Do not destroy all hope. Even though the prognosis is very poor, reassure parents that support and assistance will continue to be available for them whatever happens.
- Document each discussion and any decisions made in the notes.

Health professionals' needs

- Knowledge of the unit's policy on training and individual training needs around communication skills, sharing the news, disability and counselling.
- Knowledge of the communication policy and any local guidelines on talking to parents within the local hospital trust.
- Knowledge of the formal and informal support mechanisms with an opportunity to ask for help if needed.

Useful organisations

ACT (Association for Children with life-threatening or terminal conditions and their families)

Orchard House, Orchard Lane, Bristol BS1 5DT
Helpline: 0845 108 2201 Fax: 0117 930 4707
e-mail: info@act.org.uk
Web: www.act.org.uk

BLISS, the premature baby charity

68 South Lambeth Road, London SW8 1RL
Freephone Helpline: 0500 618 140 (10am–5pm, Mon–Fri)
Tel: 020 7820 9471 Fax: 020 7820 9567
e-mail: information@bliss.org.uk
Web: www.bliss.org.uk

Contact a Family

209–211 City Road, London EC1V 1JN
Freephone Helpline: 0808 808 3555 (10am–4pm, Mon–Fri, & Mon 5.30–7.30pm)
Fax: 020 7608 8701 Textphone: 0808 808 3556
e-mail: info@cafamily.org.uk
Web: www.cafamily.org.uk

Language Line Limited

11–21 Northdown Street, London N1 9BN
Tel: 020 7520 1430 Fax: 020 7520 1450
e-mail: enquiries@languageline.co.uk
Web: www.languageline.co.uk

SANDS (Stillbirth and Neonatal Death Society)

28 Portland Place, London W1B 1LY
Helpline: 020 7436 5881 (10am–4pm, Mon–Fri)
Tel: 020 7436 7940 Fax: 020 7436 3715
e-mail: support@uk-sands.org
Web: www.uk-sands.org

Useful resources

BLISS Parent Information Guide – Information and support for the families of sick and premature babies, 2nd edn (2004). BLISS – the premature baby charity.

McHaffie HE (2001) *Crucial Decisions at the Beginning of Life: Parents' experiences of treatment withdrawal from infants*. Radcliffe Medical Press.

Statham H, Solomou W, Green JM (2001) *When a baby has an abnormality (volume 1): a study of parents' experiences*. Centre for Family Research, University of Cambridge, Cambridge.

The Contact a Family Directory, Specific Conditions, Rare Disorders and UK Family Support Groups, annual edn. Contact a Family.

Wyatt JS (1999) Neonatal care: withholding or withdrawal of treatment in the newborn infant. *Baillieres Best Practice and Research Clinical Obstetrics and Gynaecology* **13** (4): 503–11.

Early support Information for parents – see sheet 11

Care and support at home – the role of the health visitor

Introduction

Parents may be taking their baby home from a maternity department or neonatal unit with the knowledge that further investigations and possibly ongoing medical treatment will be required. Some babies will require considerable ongoing health care. In addition to their other responsibilities, it is the parents who will be providing most of this health care at home. Parents are often still in shock, feeling isolated, guilty and anxious at this time.

The health visitor may, or may not, be meeting the parents for the first time; and may, or may not, have previously worked with a child with a similar disability or health condition. For the parents, meeting the health visitor prior to discharge (arranged by the liaison health visiting team) eases the transition from hospital care to care at home. The offer of regular contact and support will usually be much appreciated.

Key points

- Interact with the child by using his or her name, rather than focusing on the disability.
- Take time to listen to each member of the family, acknowledging the complexity of their feelings. Help individuals to accept their feelings over time.
- Be honest about your own knowledge limitations. Seek information from key health and social care colleagues, as well as conducting your own literature searches.
- Ensure that cultural differences are fully supported – offer interpreters where necessary, as well as translated literature, if possible. Further information is available from Language Line (see [Useful organisations](#)).
- Be familiar with and follow the recent DfES & DH guidelines for professionals working with disabled children (see [sheet 11](#)).

Provision of information

Parents of children with a disability or health condition enter a bewildering maze of multiple services, assessments and appointments. Most parents have no experience of the services available to them, and are unaware of their rights. Parents are very appreciative, therefore, when a health visitor signposts them to key organisations. Contact a Family is a good starting point for obtaining such information.

The health visitor also plays a key role in identifying and referring families to relevant professionals. Referrals may be to children's disability teams in social services,

community children's nurses (CCN), specialist paediatric nurses with responsibility for children with specific conditions, learning disability nurses, hospital play specialists (some of whom are attached to CCN teams), hospital based paediatric staff, paediatric pharmacists, nutritionists, paediatric physiotherapists and paediatric occupational therapists.

Key points

- Explain your role and how this relates to the roles of other professionals. With parent's permission, find out what information has already been shared. Keep the family updated of your actions.
- Check parents' understanding of their child's diagnosis and health.
- Explain the usefulness of the parent held records such as the **Early Support Family File** if appropriate (see [sheet 11](#)).
- Encourage parents to keep all correspondence on their child in date order and in the same place, preferably in a loose leaf file with plastic pockets.
- Ensure that parents know the name of their community or consultant paediatrician who takes the lead for disabled children. Copy this professional into all relevant correspondence.
- Establish good relations with relevant professionals and organisations.
- Ask if and when parents would like information on local and national support groups (see [Useful organisations](#)).
- Offer details of local social services children's disability teams, explain what these offer.
- Use other resources such as materials from Early Support, if relevant (see [sheet 11](#)).

Provision of support

Without integrated service provision, parents can feel as though each professional is addressing only one aspect of their child's needs. It is helpful therefore, when professionals work together to meet the child's and family's needs. Parents value one professional taking on the role of a key-worker, to act as the main point of contact and co-ordinate services. (see [CCNUK - sheet 11](#)). Early Support material can also help this process. (see [Early Support Family File - sheet 11](#))

Key points

- Identify whether or not parents would like one professional to act as a key worker and if so discuss this with relevant health professionals.
- Offer assistance in identifying available services including breaks from caring. Discuss the most appropriate care.
- Signpost parents to local and national voluntary organisations for financial entitlement, for example Contact a Family (see [Useful organisations](#)).
- Offer information on the Family Fund which provides grants for parents with a severely disabled or severely ill child. It can provide grants for washing machines, driving lessons, holidays and anything else related to the care of the child (see [Useful resources](#)).

Useful organisations

ACT (Association for Children with Life-Threatening or Terminal Conditions and their Families)

Orchard House, Orchard Lane, Bristol BS1 5DT
 Helpline: 0845 108 2201 (9am–4.30pm Mon, Fri)
 Fax: 0117 930 4707
 e-mail: info@act.org.uk Web: www.act.org.uk

Contact a Family

209–211 City Road, London EC1V 1JN
 Freephone Helpline: 0808 808 3555 (10am–4pm, Mon–Fri, & Mon 5.30–7.30pm)
 Fax: 020 7608 8701 Textphone: 0808 808 3556
 e-mail: info@cafamily.org.uk Web: www.cafamily.org.uk

Family Fund

Unit 4 Alpha Court, Monks Cross Drive, York YO32 9WN
 Tel: 0845 130 45 42 Fax: 01904 652625
 e-mail: info@familyfund.org.uk Web: www.familyfund.org.uk

Language Line Limited

11–21 Northdown Street, London N1 9BN
 Tel: 020 7520 1430 Fax: 020 7520 1450
 e-mail: enquiries@languageline.co.uk
 Web: www.languageline.co.uk

Useful resources

Association for Children with Life-threatening and Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health (2003) *A Guide to the Development of Children's Palliative Care Services*, 2nd edn. ACT.

Early Support—material supporting coordinated services - see [sheet 11](#)

National Primary Care Research and Development Centre (May 2000) Executive Summary 16 – Supporting families caring for a technology-dependent child in the community. www.npcrdc.man.ac.uk/Publications/Es16.pdf

Rhodes A (1999) *Promoting Partnership: Supporting disabled children who need invasive clinical procedures*. Barnados.

The Contact a Family Directory, Specific Conditions, Rare Disorders and UK Family Support Groups, annual edn. Contact a Family.

Equipment, clinical supplies and medication

The provision and maintenance of equipment is often fraught with difficulties and delays. Disputes may arise about responsibility for funding, maintenance and the locations equipment can be used.

Key points

- Be an advocate for parents obtaining appropriate equipment and supplies, including continence services. Link with other professionals as appropriate.
- With parents' permission, contact the local pharmacy regarding holding stocks of the child's medication or clinical supplies.

Child care, play group, leisure facilities and school

Parents often find it difficult to identify appropriate child care, play groups and leisure facilities. The processes relating to schooling may be confusing.

Key points

- Inform parents about appropriate local child care, play groups and leisure facilities.
- Offer parents contact details of the local Parent Partnership Officer who provides information and support on education choices.
- Liaise with the school nurse prior to the child commencing school.

Episodes of acute illness or deterioration in child's condition

Periods of acute illness and hospital care are common experiences for children with a serious health disorder or disability.

Key points

- Prepare parents for the possibility of periods of acute illness and contact with hospital services including admissions (see [Hospital care – the role of the health visitor Information Sheet 6](#)).
- Establish whether parents are aware of the signs and symptoms which need to be brought to the attention of health professionals.
- Offer to contact the GP or community children's nursing team directly (as appropriate) in order to ensure the child is seen quickly, which may prevent a hospital admission.

Hospital care – the role of the health visitor

Hospital appointments for tests, procedures, consultations and admissions are an integral part of life for many parents with a child with a serious disability or health condition. Some appointments are planned; others may be unplanned, occurring as a result of an emergency when symptoms are uncontrolled or the child's condition deteriorates. Some children receive care from a variety of health and social care professionals and long awaited appointments may be on the same day in different venues. These events can be very stressful. Parents' stress may be compounded by the additional responsibilities of caring for other children, an elderly relative, or difficulties related to work or travel. Health visitors play a key role in assisting parents in these stressful situations.

Parents can often feel guilty about asking for help. It is an enormous relief, therefore, when a health visitor becomes well informed about the family, and the other health professionals involved in the child's care. It is also helpful when health visitors liaise with the hospital professionals most closely involved in the child's care.

Parents have a right to be with their child whenever their child receives hospital care (unless a general anaesthetic is being given). There may be times during an admission, however, when a parent cannot be present. In these circumstances, it is helpful if parents prepare information about their child prior to admission. This might include providing a description of the ways in which the child communicates pain or hunger, or the name by which the child prefers to be called or a favourite drink (or 'comforter'). The **Early Support Family File** is a useful tool to facilitate this - see [sheet 11](#). Alternatively after admission a list of likes and dislikes can be expanded and hung on the child's hospital bed.

Many hospitals produce resources and/or activities to assist the child and siblings before a planned admission. Organisations such as Action for Sick Children produce a range of relevant resources (see [Useful organisations](#)).

Key points

- Be aware that many parents have become experts in their child's care. Listen to and value this knowledge. Encourage parents to utilise their expertise, for example, in preparing information about their child prior to a hospital admission.
- If there is a recurrence of a particular medical problem or a specified health issues confirm whether the child has priority or direct access to a specific ward.
- With parents' permission, liaise with appropriate hospital staff.
- Maintain regular contact with hospital services providing relevant information and facilitating early discharge.
- Establish contact with other professionals for advice and information. Parents are reassured by the knowledge that health and social care professionals are working together and pooling their knowledge and skills.
- Offer assistance in formulating questions for relevant health professionals. Recognise that whilst parents may think of questions at the time of caring for their child, they may fail to recall these at the time of a hospital appointment.
- Underscore the value of Parent Held Records such as the child's Early Support Family File. This will help parents and professionals understand the child's physical condition and clinical care.
- Recognise that some parents will want more detailed information than others. Tailor information to respective need.
- Re-iterate the advantages of having all relevant correspondence at each hospital appointment or admission.
- Encourage parents to keep their own records and offer assistance in maintaining records.
- Communicate the importance of clearly documented information.
- Remind other professionals to make use of 'Parent Held Records' such as the **Early Support Family File** and update as appropriate.
- Identify whether parents have been offered details of relevant support groups; offer information as appropriate.
- Ensure parents are aware of procedures for claiming travelling costs, where relevant. Offer information about claiming hospital visiting costs, local transport schemes and voluntary sector organisations. Contact a Family and the Family Fund can give relevant advice (see [Useful organisations](#)).
- Ensure that cultural differences are fully supported – offer interpreters or health advocates where necessary, as well as relevant translated literature, where possible. Further information is available from Language Line (see [Useful organisations](#)).

Keeping things going at home

Whilst the benefits of encouraging parents to stay with their child in hospital are well known, tensions can arise in relation to other responsibilities.

Key points

- Signpost parents to local and national voluntary organisations which offer advice on benefits and financial entitlement. Some benefits may be affected by their child's admission to hospital. The Contact a Family helpline offers advice on this (see [Useful organisations](#)).
- Inform working parents of their rights for parental leave, flexible leave and time off for dependents. The Contact a Family helpline offers advice on this (see [Useful organisations](#)).
- Offer assistance in identifying suitable childcare.
- If families are unhappy with their child's care, encourage them to talk to relevant staff. Offer to accompany them to meetings, or encourage parents to talk to the Patient Advice and Liaison Service (PALS) (see [Useful resources](#)).

Useful organisations

Action for Sick Children (England and Wales)

No 3 Abbey Business Centre, Keats Lane, Earl Shilton,
Leicestershire LE9 7DQ
Tel: 01455 845 600
e-mail: enquiries@actionforsickchildren.org
Web: www.actionforsickchildren.org

Action for Sick Children (Scotland)

172 Leith Walk, Edinburgh, EH6 5EA
Tel: 0131 553 6553
e-mail: enquiries@ascscotland.org.uk
web: www.ascscotland.org.uk

Contact a Family

209–211 City Road, London EC1V 1JN
Freephone Helpline: 0808 808 3555 (10am–4pm, Mon–Fri,
Mon 5.30–7.30pm)
Fax: 020 7608 8701
Textphone: 0808 808 3556
e-mail: info@cafamilly.org.uk
Web: www.cafamilly.org.uk

Family Fund

Unit 4 Alpha Court, Monks Cross Drive, York YO32 9WN
Tel: 0845 130 45 42 Fax: 01904 652625
e-mail: info@familyfund.org.uk
Web: www.familyfund.org.uk

Language Line Limited

11–21 Northdown Street, London N1 9BN
Tel: 020 7520 1430
Fax: 020 7520 1450
e-mail: enquiries@languageline.co.uk
Web: www.languageline.co.uk

Useful resources

National Service Framework (NSF) for children and young people www.dh.gov.uk Use the A-Z site index from the home page to find all documents including standard 8 for disabled children and young people and those with complex health needs.

The Early Support Family File - see [sheet 11](#)

PALS are hospital based advice and advocacy services which have access to in-house databases and information sources. Information about local PALS services can be obtained from hospitals, clinics, GP surgeries, health centres, NHS Direct. Tel: 0845 4647 or NHS Direct website – www.nhsdirect.nhs.uk

The Contact a Family Directory, Specific Conditions, Rare Disorders and UK Family Support Groups, annual edn. Contact a Family.

Health for all children 4: Guidance on implementation in Scotland, Scottish Executive 2005, www.scotland.gov.uk

Delivering for Health, Scottish Executive 2005, www.scotland.gov.uk (SEHD Action Framework from the National Framework for Service Change in the NHS in Scotland)

Referral to a genetics clinic

This information sheet is intended for all health professionals making a neonatal or paediatric referral to a genetics clinic.

Parents may feel confused by the offer of a referral to a genetics clinic immediately, or soon after, their child's birth, or on first receiving their child's diagnosis. Whilst they may welcome the opportunity to have a diagnosis confirmed, tensions can arise around whose side of the

family the condition has come from. Parents may blame themselves or each other. Many families feel anxious because this appointment, or event, is outside their everyday experience. Some may even feel that it could lead to social stigma, shame or guilt. With this in mind, it is important that the referral process is transparent and conveyed to families in a way they understand.

Many parents attend a genetics appointment because they want a diagnosis and to find out why this has happened. They want their concerns to be acknowledged. A few parents will want a genetics appointment to identify the gene alteration in the family and to discuss any possible risk to other family members. Some may attend hoping for an increased certainty where, in fact, this may not be possible. For others, a genetics appointment can seem like yet another appointment with another specialist and further repetition of information. Some parents may have little idea about what to expect from their appointment and this lack of understanding can make it difficult for them to formulate questions in advance.

There is very little research into what parents need to know or the kind of support they may need at the time of referral to a genetics clinic. Contact a Family has drawn up an 'action list' (see overleaf), which has been compiled from the observations of health professionals, workers in the voluntary sector and parents. This list will hopefully serve as a useful training resource or as the basis of an audit trail for parents' information and support needs at the time of referral.

Useful organisations

British Society for Human Genetics (BSHG)

Clinical Genetics Unit, Birmingham Women's Hospital
Birmingham B15 2TG
Tel/Fax: 0121 627 2634 Fax: 0121 623 6971
e-mail: bshg@bshg.org.uk Web: www.bshg.org.uk

Contact a Family

209–211 City Road, London EC1V 1JN
Freephone Helpline: 0808 808 3555 (10am–4pm, Mon–Fri, & Mon 5.30–7.30pm)
Fax: 020 7608 8701 Textphone: 0808 808 3556
e-mail: info@cafamily.org.uk Web: www.cafamily.org.uk

Genetic Interest Group (GIG)

Unit 4D, Leroy House, 436 Essex Road, London N1 3QP
Tel: 020 7704 3141 Fax: 020 7359 1447
e-mail: post@gig.org.uk Web: www.gig.org.uk

Unique – Rare Chromosome Disorder Support Group

PO Box 2189, Caterham, Surrey CR3 5GN
Tel/Fax: 01883 330 766
e-mail: info@rarechromo.org Web: www.rarechromo.org

Useful resources

Barr O, Millar R (2003) Parents of Children with Intellectual Disabilities: Their Expectations and Experience of Genetic Counselling. *Journal of Applied Research in Intellectual Disabilities* **16** (3): 189–204.

Contact a Family Factsheet: A Genetic Condition in the Family. www.cafamily.org.uk/genetics.html
Contact a Family: Internet Leaflet www.cafamily.org.uk/paptinternetleaflet.pdf

Genetic Interest Group (GIG) Meeting the needs of patients and their families – A patient centred checklist for clinical genetics. www.gig.org.uk/docs/gig_clinical.pdf

Skirton H, Patch C (2002) *Genetics for Healthcare Professionals: A lifestyle approach*. Bios, Oxford.

Skirton H (2001) The client's perspective of genetic counselling – A grounded theory study. *Journal of Genetic Counselling* **10** (4): 311–329.

The Contact a Family Directory, Specific Conditions, Rare Disorders and UK Family Support Groups, annual edn. Contact a Family.

Searching for information on the Internet

Prior to a genetics appointment, parents may search for information on the Internet. It is useful if they are directed towards the websites of reputable institutions such as hospitals, universities or a government body. Good medical information will be authored and dated. It is helpful if parents are reminded that not all the information they find will be relevant to them and that such information should be discussed with the consultant or counsellor at their appointment. Guidelines for evaluating medical information can also be provided. The Contact a Family internet leaflet provides guidance to families on evaluating sources of medical information and directs them to reliable websites. (See useful resources.) For more detail on internet use, see sheet 10.

Action list: referral to a genetics clinic

The following has been discussed.

- A clear explanation of why the patient is being referred.
- An outline of what is likely to happen at a genetics appointment:
 - family history
 - physical examination/photograph
 - offer of testing, if requested and available.
- A diagnosis may not always be confirmed with a test.
- An explanation of why family history is important.
- An explanation of the difference between genetic counselling and therapeutic counselling. Genetic counselling has been defined as, "A communication process which deals with human problems associated with the occurrence or the risk of occurrence, of a genetic disorder in a family". (American Society of Human Genetics, 1975)
- The process of genetic referral within the region e.g. is there a home visit?
- How long a family will be in the clinic at a genetics appointment.
- The estimated waiting time for the:
 - genetics appointment (1 week, 1 month, 3 months)
 - results of investigations (not always known)
- Information about a pre-clinic leaflet to be sent by the genetics centre prior to the appointment.
- Information about a summary letter which will be sent to the patient, referring clinician and GP.
- Suggestion of taking a partner, friend or close relative along to the appointment.
- Help in formulating relevant questions prior to the genetics appointment.
- Details of a health professional or voluntary organisation who may be contacted prior to the appointment
- Patient questions.
- Offer of further information in the patient's language e.g. London IDEAS Translation Project. The London IDEAS Translation Project is currently developing accessible patient information leaflets and audiotapes in up to 12 languages about issues relating to genetics and genetic services. For more information, go to the London IDEAS website: www.londonideas.org
- Offer of written information on:
 - Genetic counselling e.g. A Genetic Condition in the Family, Contact a Family www.cafamily.org.uk/genetics.html
 - Helpful questions e.g. *Has your child a genetic disorder – What do you need to know from whom?* Genetic Interest Group www.gig.org.uk/docs/consortium-leaflet.pdf
 - Chromosomes e.g. The Little Yellow Book: A Guide to Rare Chromosome Disorders (vol 1), Unique (see [Useful organisations](#)).

Patient name/hospital number

Referring clinician

Date

Printed by Contact a Family, 209-211 City Road, London EC1V 1JN

Support for fathers, siblings and grandparents

This information sheet is intended for all health professionals meeting families.

All members of the family, whatever the family network, are affected when a child has a disability, medical condition or rare disorder. As such, family members can feel isolated and let down if their needs for information and support are not met at significant times in the child's life.

Fathers

Fathers play an integral role in the family when a child is disabled. However, many fathers feel excluded from certain aspects of the child's care. They often feel that the support systems in place are more beneficial for their partners. A diagnosis may be given without a father being informed or present; or meetings may be regularly arranged at times he cannot attend. The result is that a father can feel he has missed out on key information.

When information is given, it is important to include the father whenever possible. He too is part of a wider network of family members and friends and may have to relay information. Improved support, information and the opportunity to access services can result in a father feeling much more involved in the care of his child. Fathers can feel particularly isolated when they are not meeting other fathers in a similar situation. This may be particularly true for fathers who are the main carer or who have left the family home.

Key points

- Recognise the father's need for support and inclusion at significant times.
- Keep fathers as fully informed as possible and offer support as appropriate. This helps them feel included in their child's care.
- Be aware that family structure varies and that some families are father-led. There may be a step-father as well as a biological father to inform.
- If the father is unable to attend, offer a tape recording of the consultation or offer to call. Also offer father-specific information to the mother to pass on to him (see [Useful resources](#)).
- Whenever possible, arrange meetings at home. This will allow fathers, siblings and other family members, such as grandparents, to share information and offer mutual support. This may also strengthen family relations.
- When parents attend together, recognise that fathers and mothers are likely to absorb information at different rates, and express different concerns. They may well grieve in different ways and at different times. Tailor information and support to the needs of the father as well as the mother.
- Ask if and when fathers would like information on support groups or national organisations, such as a condition-specific group. Fathers might find it helpful to meet other fathers in a similar situation (see [Useful organisations](#)).
- Ensure that cultural differences are fully supported – offer interpreters or health advocates where necessary, as well as relevant translated literature, where possible. Further information is available from Language Line (see [Useful organisations](#)).
- Be aware of conflict between parents.
- If appropriate, offer a referral to a specialist adviser on employment issues for advice on returning to work and employment rights (see [Useful resources](#)).

Siblings

Brothers and sisters share many of their parents' concerns. Some siblings share the responsibility for the additional care needs of their brother or sister. As a result, they may have less time for themselves, to play with their friends or do their homework. Some siblings may not fully understand the disability themselves and may struggle with explanations to classmates and friends. They may also have misconceptions about the condition.

Key points

- Offer age-appropriate written material that addresses issues faced by siblings, such as getting used to a new baby or grieving the loss of a brother or sister (see [Useful resources](#)).
- Aim to provide support that is flexible enough to accommodate the needs of siblings as well as the disabled child and their parents. Young siblings, for example, will need simple, clear information that helps them to fully understand their brother or sister's disability.
- Identify whether a sibling support group or young carers group is available. Some condition-specific organisations offer the opportunity for siblings to get in touch with each other. They may also run workshops on sibling issues (see [Useful resources](#)).

- Ascertain how siblings are progressing at school; and where appropriate contact the teacher with parents' permission.
- Visit the family when siblings are at home. Ask them questions about how they are getting on at school and with their friends. Ask them about their hobbies. This will help them know that they are special too.
- Encourage families to include siblings. Parents may need help in responding to siblings' questions; encourage them to be honest in their responses.
- Offer to facilitate a family discussion to help the family formulate a plan for future care.

Grandparents

Grandparents may find themselves in an unfamiliar and difficult situation. It may be that they are struggling to come to terms with their grandchild's disability. They may also be distressed by their son or daughter's own concerns. Some grandparents become very closely involved whilst others find this difficult and withdraw. Grandparents often feel responsible if the condition is found to be genetic.

Grandparents may feel excluded from the normal information networks available to parents. As a result, they often turn to the parents for information about the child.

Key points

- Be aware that if a grandparent is well informed about a disability or health condition, this knowledge and understanding can be an asset to the entire family.
- Offer details of a local or national grandparents' support group. Contact a Family produces a factsheet containing advice for grandparents (see [Useful resources](#)).
- Recognise the need to strike a balance between involving grandparents and respecting the primary carers' wishes.
- Ensure that everyone knows what is happening. Support from family and friends is valued by parents.

Relationships

The impact of caring for a disabled child can put considerable strain on family relationships. Contact a Family have a factsheet that is intended as a useful guide for parents of disabled children struggling with relationship issues. (See [useful resources](#))

Useful organisations

ACT (Association for Children with Life-Threatening or Terminal Conditions and their Families)

Orchard House, Orchard Lane, Bristol BS1 5DT
 Helpline: 0845 108 2201 Fax: 0117 930 4707
 e-mail: info@act.org.uk
 Web: www.act.org.uk

Contact a Family 209–211 City Road, London EC1V 1JN

Freephone Helpline: 0808 808 3555 (10am–4pm, Mon–Fri, Mon 5.30–7.30pm)
 Fax: 020 7608 8701 Textphone: 0808 808 3556
 e-mail: info@cafamily.org.uk Web: www.cafamily.org.uk

Fathers Direct Web: www.fathersdirect.com

Genetic Interest Group (GIG)

Unit 4D, Leroy House, 436 Essex Road, London N1 3QP
 Tel: 020 7704 3141 Fax: 0207 359 1447
 e-mail: post@gig.org.uk Web: www.gig.org.uk

Grandparents Plus

18 Victoria Park Square, Bethnal Green, London E2 9PF
 Tel: 020 8981 8001
 e-mail: info@grandparentsplus.org.uk
 Web: www.grandparentsplus.org.uk

Language Line Limited

11–21 Northdown Street, London N1 9BN
 Tel: 020 7520 1430 Fax: 020 7520 1450
 e-mail: enquiries@languageline.co.uk
 Web: www.languageline.co.uk

Sibs Meadowfield, Oxenhope, West Yorkshire BD22 9JD

Tel: 01535 645 453 Fax: 01904 652625
 e-mail: info@sibs.org.uk Web: www.sibs.org.uk

The Child Bereavement Trust

Aston House, West Wycombe, High Wycombe, Bucks HP14 3AG
 Helpline: 0845 357 1000
 Tel: 01494 446 648 Fax: 01494 440 057
 e-mail: enquiries@childbereavement.org.uk
 Web: www.childbereavement.org.uk

Useful resources

Contact a Family Factsheet: Fathers
www.cafamily.org.uk/fathers.html

Contact a Family Factsheet: Siblings
www.cafamily.org.uk/siblings.html

Contact a Family Factsheet:
www.cafamily.org.uk/grandparents.html

Contact a Family Factsheet: Working and caring for a disabled child. www.cafamily.org.uk/employment.html

Contact a Family Factsheet: Relationships and caring for a disabled child. www.cafamily.org.uk/relationships.html

Meyer DJ (editor) (1995) *Uncommon Fathers: Reflections on Raising a Child with a Disability*. Woodbine House.

The Child Bereavement Trust Factsheet: Understanding bereaved children and young people.
www.childbereavement.org.uk/uploads/articles/Bereaved_Children_6pp.pdf

West S (2000) *Just a Shadow: A review of support for the fathers of children with disabilities*. The Handsel Trust.

Good practice in sharing news

“I think that conveying difficult news to parents is just as much of an art form as doing an operation and it’s just as important to be self-critical”

Professor Sir David Hall, President of the Royal College of Paediatrics and Child Health 2000–2003

It is widely known that sharing significant news with parents about a child is a challenging task requiring skill and sensitivity. Whether there is an established existing relationship, or news is shared at the first meeting, this is likely to be one of the most significant pieces of information parents ever receive.

It is often helpful to see sharing concerns with parents as a process, rather than a single event. Before, during and after this process, it is important to be aware of the messages communicated both verbally and non-verbally to parents. Parents’ experience at this time can have a huge impact on them and their child’s future. It may also influence:

- How parents share news with friends and other family members
- Parents’ ability to respond to their new situation
- Future working relationships with professionals
- Parents’ expectations of their child.

Right From The Start

Right From The Start (RFTS) is a national initiative that aims to promote good practice at the time news is shared with families of a child’s additional needs. This news could be concerns about a child’s development, a diagnosis of a physical or sensory impairment, learning difficulty or information regarding a child’s complex health needs. The work of RFTS has been developed in partnership with parents, professionals and disabled people and is informed by a report (Leonard 1994) which examined the experiences of parents at or around the time of diagnosis in their children.

The RFTS project acknowledges that sometimes children and their families live without a diagnosis. In some situations, it may be necessary to do tests before a diagnosis can be given or confirmed. Honest, transparent communication is critical to developing an effective partnership between parents, health professionals and the child.

The project has developed key principles for professionals sharing news with families. It also promotes a good practice framework and a range of

resources and training materials to support sensitive practice at this time. The points outlined below are based on the RFTS template:

Value the child – as a child first, their condition or disability second:

- Always use the child’s name
- Avoid predictions and pronouncements about the child’s future
- When sharing news, keep the baby or child with the parents whenever possible
- When sharing news about an older child, consider whether the child should be present.

Respect parents and families:

- Support and empower parents
- Listen to parents and share information sensitively and honestly
- Treat parents’ concerns seriously
- Use plain, understandable language and give explanations
- Discuss prognostic uncertainties openly and provide opportunities to ask questions
- Check the parents’ understanding of the situation
- Ensure there is an appropriate follow-up and provide any additional information needed
- Acknowledge and respect cultural differences.

Support for professionals:

- Acknowledge and address personal and professional development needs
- Ensure continuous personal and professional development
- Give opportunities for debriefing for all team members
- Use peer support and critical reflection to inform and enhance practice.

The key points are based on the RFTS Template – good practice in sharing the news. To find out more about RFTS visit

<http://www.scope.org.uk/earlyyears/prof/start.shtml>
or e-mail: rfts@scope.org.uk

Training packs and courses

ARC (Antenatal Results and Choices) Communication skills and breaking bad news: The implications of antenatal screening and testing. One day training course.

Child Bereavement Trust (2004) Paediatric Post Mortem: Communicating with Grieving Families. A two-part training video or CD Rom for all those whose work brings them into contact with bereaved families when a baby or child dies. Child Bereavement Trust.

Right From The Start,
<http://www.scope.org.uk/earlyyears/prof/start.shtml>

Shah R (1998) Sharing The News: A good practice guide and training pack for professionals working with Asian families when they are told about their child's disability. Mental Health Foundation

West Birmingham Portage Service (2003) Sharing Concerns: giving, hearing and living with the news of a child's disability. A training video and resource pack. West Birmingham Portage Service

Useful resources

Abramsky L, Hall S, Levitan J, Marteau TM (2001) What parents are told after prenatal diagnosis of a sex chromosome abnormality: interview and questionnaire study. *British Medical Journal* **322** (7284): 463–6.

Aspinall CL (2002) Dealing with the prenatal diagnosis of clefting: a parent's perspective. *The Cleft Palate-Craniofacial Journal* **39** (2): 183–7.

Buckman R (1992) *How to Break Bad News: A Guide for Health Professionals*. Parthenon Publications Group.

Contact a Family factsheet: Living Without a Diagnosis
www.cafamily.org.uk/undiagno.html

Kerr SM, McIntosh JB (1998) Disclosure of disability: exploring the perspectives of parents. *Midwifery* **14** (4): 225–232.

Leonard A (1994) Right From The Start: Looking at diagnosis and disclosure – Parents describe how they found out about their child's disability.
www.rightfromthestart.org.uk/docs/rfts_report.pdf

Pearson D, Simms K, Ainsworth C, Hill S (1999) Disclosing special needs to parents. Have we got it right yet? *Child: Care, Health and Development* **25** (1): 3–13.

Public Health Genetics Unit, **Parents as Partners: A report and guidelines on the investigation of children with developmental delay; by parents, for professionals, Cambridge Genetics Knowledge Park, 2006**

Robb F (1999) Congenital malformations: breaking the bad news. *British Journal of Midwifery* **7** (1): 26–31.

Useful organisations

ACT Association for Children with Life-Threatening or Terminal Conditions and their Families

Orchard House, Orchard Lane, Bristol BS1 5DT
 Helpline: 0845 108 2201 Fax: 0117 930 4707
 e-mail: info@act.org.uk
 Web: www.act.org.uk

ARC (Antenatal Results and Choices)

73–75 Charlotte Street, London W1T 4PN
 Helpline: 020 7631 0285 (10am–5.30pm, Mon–Fri)
 Tel/Fax: 020 7631 0280
 e-mail: info@arc-uk.org Web: www.arc-uk.org

Capability Scotland

11 Ellersly Road, Edinburgh EH12 6HY
 Tel: 0131 313 5510 Fax: 0131 346 1681
 Web: www.capability-scotland.org.uk

Contact a Family

209–211 City Road, London EC1V 1JN
 Freephone Helpline: 0808 808 3555 (10am–4pm, Mon–Fri, & Mon 5.30–7.30pm)
 Fax: 020 7608 8701 Textphone: 0808 808 3556
 e-mail: info@cafamily.org.uk Web: www.cafamily.org.uk

Language Line Limited

11–21 Northdown Street, London N1 9BN
 Tel: 020 7520 1430 Fax: 020 7520 1450
 e-mail: enquiries@languageline.co.uk
 Web: www.languageline.co.uk

Mental Health Foundation

Foundation Sea Containers House, 20 Upper Ground, London SE1 9QB
 Tel: 020 7803 1100 Fax: 020 7803 1111
 e-mail: mhf@mhf.org.uk Web: www.mentalhealth.org.uk

National Portage Association

PO Box 3075, Yeovil BA21 3FB
 Tel/Fax: 01935 471641 (9am–1pm, Mon and Thurs)
 e-mail: info@portage.org.uk Web: www.portage.org.uk

SANDS (Stillbirth and Neonatal Death Society)

28 Portland Place, London W1B 1LY
 Helpline: 020 7436 5881 (10am–4pm, Mon–Fri)
 Tel: 020 7436 7940 Fax: 020 7436 3715
 e-mail: support@uk-sands.org Web: www.uk-sands.org

Scope

6 Market Road, London N7 9PW
 Helpline: 0808 800 3333 (9am–9pm Mon–Fri, 2–6pm Sat–Sun)
 Tel: 0207 619 7100
 e-mail: cphelpline@scope.org.uk Web: www.scope.org.uk

SWAN (Syndromes Without A Name)

6 Acorn Close, Great Wyrley, Walsall WS6 6HP
 Tel/Fax: 01922 701 234
 e-mail: info@undiagnosed.org.uk
 Web: www.undiagnosed.org.uk

The Child Bereavement Trust

Aston House, West Wycombe, High Wycombe, Bucks HP14 3AG
 Tel: 0845 357 1000 Fax: 01494 440 057
 e-mail: enquiries@childbereavement.org.uk
 Web: www.childbereavement.org.uk

Contact a Family and other sources of information

Contact a Family

Contact a Family is a UK charity providing support, advice and information to families with a disabled child including children with a physical, learning or behavioural disability or any ongoing health condition. The charity has specialist information on rare conditions and support groups and has a database of over 2,000 conditions containing evaluated information and will undertake literature searches on any other conditions for enquirers. They can provide advice to families on a wide range of topics including getting help with finance, education and leisure. Contact a Family links parents on an one-to-one basis where no support group currently exists.

Contact a Family operates on a confidential national freephone helpline for professionals and parents from Monday to Friday 10am-4pm, Mon 5.30pm-7.30pm

Contact details:

Freephone Helpline: 0808 808 3555

Textphone: 0808 808 3556

Email: helpline@cafamily.org.uk

Post: 209-211 City Road, London EC1V 1JN

Internet resources

Contact a Family's website

www.cafamily.org.uk includes:

- The online Contact a Family Directory containing regularly reviewed, authored and dated information on over 360 disorders, many very rare, together with details of support organisations.
- An extensive range of factsheets available to download.
- Information about Contact a Family's national, regional and local offices.
- Signposting to other sources of information and support.

Other sources of family support

www.act.org.uk ACT, support for families of children with life threatening conditions

www.arc-uk.org Information and support for parents throughout the antenatal testing process

www.bliss.org.uk Support for families of premature babies

www.childbereavement.org.uk Information for bereaved young people and families, and professionals

www.uk-sands.org Support for parents and families whose baby is stillborn or dies soon after birth

Keypoints

- Use Contact a Family if there is information you need.
- Tell families about Contact a Family – Leaflets are available from Contact a Family to assist with this.

Professional portals

www.dh.gov.uk Gives access to the index of all governmental organisations such as the Department of Health (DH), information and full texts of DH publications, Health of the Nation targets, helplines.

www.nelh.nhs.uk UK National electronic Library of Health (NeLH) is the portal to all Specialist Libraries (formerly Virtual Branch Libraries) for Child Health and Learning Disability, the Cochrane Library collection of systematic reviews, databases and NHS information.

www.nih.gov/icd Gives links to all the US National Institutes of Health with searchable databases.

omni.ac.uk Gives access to fully evaluated health sites.

www.premature-infant.com/resources.html – information on neonatal issues.

Patient portals

www.ich.ucl.ac.uk Contains an extensive archive of paediatric resources and the latest in care and research developments.

www.nhsdirect.nhs.uk The online arm of the National Health Service.

Information on specific disorders for professionals and patients

www.ninds.nih.gov/health_and_medical/disorder_index.htm Excellent information on a range of neurological disorders provided by the US National Institutes of Health with further links to research papers.

www.nlm.nih.gov/medlineplus Extensive US National Library of Medicine encyclopaedia and health topic collection.

www.nlm.nih.gov/mesh/jablonski/syndrome_db.html Extensive range of information on learning disblement disorders from the US National Library of Medicine.

www.rarediseases.org/search/rdbsearch.html The site of NORD (National Organization for Rare Disorders) gives access to a database of abstracts of information on a huge range of disorders.

Evaluating information on the Internet

There is a huge amount of information available on-line. Assistance in evaluating this information is found at:

www.judgehealth.org.uk

Contact a Family and the Information Management Research Institute (IMRI), School of Informatics, Northumbria University have produced award winning guidelines for consumers searching for medical information on the Internet.

The guidelines cover:

- the need for the name and background of the author and dated information. For example Medical texts in the Contact a Family Directory carry endorsements in the following form:
Medical text last updated April 2004 by Dr R Auer, LRF Clinician Scientist, Barts & The London Queen Mary School of Medicine, London, UK
- details about the website producer and funder
- contact details or web links to cited organisations
- who the information is aimed at
- the design and accessibility of the site by people with visual and other impairments

The full guidelines and summaries can be found at the address above.

www.hiquality.org.uk/guide/evidence2.htm

This website is produced by the government funded Centre for Health Information Quality. The information is appropriate for professionals who want to refer to the evidence base, references and peer reviews. More information can be found at the address above.

Information for families on using the internet

Families often search the internet to find out more about their child's condition. It is important they know how to evaluate medical information found there. Contact a family can provide leaflets for health professionals to give to families which provide guidance based on the principles above.

www.cafamily.org.uk/paptinternetleaflet.pdf

Library/information services

Details of hospital libraries can be found by accessing the National electronic Library for Health (NeLH) Librarian Portal – www.nelh.nhs.uk/librarian/default.asp Hospital libraries provide enquirers with a full range of library services in person, by telephone or email. Most professional organisations will have a library or information service. Examples are:

- Chartered Society of Physiotherapy Library & Information Service www.csp.org.uk
- The Midwives Information and Resource Service (MIDIRS) www.midirs.org
- Royal College of Midwives Information Centre www.rcm.org.uk
- Royal College of Speech Therapists' Information Office www.rcslt.org/info.shtml

Useful organisations

Children in Scotland

Princes House, 5 Shadwick Place, Edinburgh EH2 4RG
Tel: 0131 228 8484 Fax: 0131 228 8585
www.childreninscotland.org.uk

Council for Disabled Children

c/o National Children's Bureau
8 Wakley Street, London EC1V 7QE
Tel: 020 7843 1900 Fax: 020 7843 6313
email: cdc@ncb.org.uk Web: www.ncb.org.uk/cdc/

Language Line Limited

11–21 Northdown Street, London N1 9BN
Tel: 020 7520 1430 Fax: 020 7520 1450
e-mail: enquiries@languageline.co.uk
Web: www.languageline.co.uk

National Children's Bureau

8 Wakley Street, London EC1V 7QE
Tel: 020 7843 6000 Fax: 020 7278 9512
Web: www.ncb.org.uk

National Service Framework (NSF) for children and young people.

www.dh.gov.uk Use the A-Z Site Index from the home page, to find all documents including standard 8 for disabled children and young people and those with complex health needs

Wellcome Trust Information Service

210 Euston Road, London NW1 2BE
Tel: 020 7611 8722 Fax: 020 7611 8369
e-mail: library@wellcome.ac.uk
Web: <http://library.wellcome.ac.uk/>

Early Support

This information sheet is intended for all professionals meeting families with disabled children in England.

Children who are born with a disability will require ongoing support and services as they grow up. It is important that families with very young children know about community based services and support, particularly if they have spent long periods of time in hospital. Health professionals should guide parents to appropriate services and ensure that information is available to help them through the early years.

Research into the needs of families of disabled children show very consistent messages. Families find it difficult to

- Find out about services that are available to help them
- Make sense of the role of different agencies and professionals
- Get professionals to understand their situation and needs in the context of the whole family
- Have their own knowledge of their child recognised

A lack of coordinated approach between professionals involved in the child's care provides additional problems for the families already complicated lives.

"We see 20 specialists contributing to our child's care. You tell your story over and over again. Sometimes it feels like a full-time job just communicating with them all."

What is Early support?

The role of the Early Support program is to encourage agencies and services to work together to support families and provide practical tools and principles to support this process. Early Support materials (see overleaf) can be used flexibly in whatever way is most useful for individual families. The material is already being used by professionals working within medical, therapeutic, Early Years, Sure Start and childcare communities. Amongst those who might benefit most are

- Infants discharged from hospital where families need prompt, practical help to care for a child with medical and other needs in the home
- Children whose additional support needs emerge only with time
- Those with obvious, on-going and multiple additional support needs
- Children with an obvious additional support need, but no 'diagnosis'.

Early Support

Is the central Government mechanism for achieving better co-ordinated, family-focused services for disabled young children and their families.

Early Support was developed as a means of implementing the Government guidance for professionals working with disabled children – **Together from the start** (DoH/FDfES, 2003).

It is integral to the restructuring of Children's Services in response to **Every Child Matters** and facilitates the achievement of objectives set by a broad range of Government policy documents aimed at the delivery of services for young disabled children and their families including the **National Service Framework for Children**. Early Support has been developed initially for children 0-3 but children's centres and service providers across England are being advised that its principles and materials can be extended in their application to children aged 0-5.

www.earlysupport.org.uk

Keypoints

- Visit the Early Support program website at www.earlysupport.org.uk to find out more about the Early Support program and view their material.
- Order printed versions of the material which is available free of charge to parents of young disabled children living in England and professionals working with such families. (See overleaf)
- Find out more from the website, or by contacting your local children's centre or Social Services Children's Disability team, whether others in your area are already using the Early Support program and link up with them.
- If there is no Early Support program running in your area, discuss with your team how you might make use of the material and/or introduce an Early Support Program.

Early Support materials

See table for details of ordering

A range of disability/ condition specific booklets for parents can be used to provide initial information to parents about their child’s condition/disability and sources of further information and support. See below for list of conditions/disabilities.

The **Early Support Family pack** informs parents about the services available to support them and also contains the **Early Support Family file**. This is a standard family held record that supports

- Better co-ordination of services provided for the child and family
- More effective exchange of information between professionals working with the family.
- Reducing the number of times the family have to repeat their story.

At the heart of the file is a **Family Service Plan** which encourage all the agencies working with a family to discuss the support that is being provided and to agree priorities. The **pack is not normally read in isolation** and families get the best out of it when it is explained by someone they know and trust over a period of time.

The **Early Support Professional guidance** is essential reading for anybody who works with families with very young disabled children, including paediatricians, health visitors, nurses, speech and language therapists, portage workers, physiotherapists, psychologists and occupational therapists. It shows how

- The principles set out *Together from the Start* can be applied flexibly in many different organisational settings
- The Early Support materials can be used to assist at operational level
- Multi-agency planning at strategic level supports service development.

The **Early Support Monitoring protocol for deaf babies and children** material is designed for families with a young hearing impaired child and for the professionals who work with them to track development for the first 3 years of life. The accompanying guide **‘How to use this protocol’** should always be read alongside.

Two new monitoring protocols, are currently being piloted to support families and the professionals working with children with **Down syndrome** and children who are **visually impaired**.

The **Early Support Service audit tool** enables service providers to measure the quality of the service they are providing and plan for improvement. The tool is a multi-agency, pan-disciplinary instrument to audit current service provision at local level, plan for development and inspect service provision.

Key workers

Early Support promotes and facilitates the development of key worker services for families with young and disabled children. **The Early Support Family Pack** is specifically designed to help those taking on a key worker role to deliver an effective service to families (see useful resources: Care Coordination network UK).

Ordering Early Support Materials: These can be ordered direct from the Early Years support website at www.earlysupport.org.uk or by contacting DfES publications quoting the appropriate reference numbers. DfES Publications, PO Box 5050, Sherwood Park, Annesley, Nottingham, NG15 0DJ, UK
Tel: 0845 602 2260 e-mail: dfes@prolog.uk.com

Information for Parents Booklets:	Reference
Autistic Spectrum Disorder	ESPP12
Cerebral Palsy	ESPP10
Deafness	ESPP11
Down Syndrome	ESPP13
Learning Disabilities	ESPP15
When Your Child Has No Diagnosis	ESPP16
Multi-Sensory Impairment	ESPP9
If Your Child Has a Rare Condition	ESPP18
Speech and Languages Difficulties	ESPP14
Visual Impairment	ESPP8
Early Support Family Pack	ESPP1
Early Support Professional guidance	ESPP3
Early Support Monitoring protocol for deaf babies & children	ESPP29 & ESPP30
Early Support Service audit tool	ESPP34 & ESPP35

Useful resources

Care Co-ordination Network UK (CCNUK) is an umbrella organisation promoting and supporting care co-ordination or key working for disabled children and their families in England, Northern Ireland, Scotland and Wales. Address: Social Policy Research Unit, University of York, Heslington, York YO10 5DD Tel: 01904 321959
email: info@ccnuk.org.uk Web: www.ccnuk.org.uk

Every Child Matters Provides information on programs supporting children and young people from birth to age 19 via the development of multi-agency services. Web: www.everychildmatters.gov.uk

National Service Framework for Children, Young People and Maternity Services: Standard 8 - disabled children and young people and those with complex health needs, 2005 Web: www.dh.gov.uk – search on ‘NSF Standard 8’.

Sure Start Is the government program to deliver the best start in life for every child and brings together, early education, childcare, health and family support. Web: www.surestart.gov.uk

Together from the start (2003) Practical guidance for professionals working with disabled children (from birth to third birthday) and their families Web: www.dh.gov.uk – Search on ‘Together from the Start’.
Tel: 020