

CUTTING THROUGH THE INFORMATION OVERLOAD TO SUPPORT PATIENTS AND THEIR FAMILIES

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A charity for families of disabled children has teamed up with leading Paediatricians to help health professionals meet their patients' needs.

UK charity Contact a Family and the Royal College of Paediatrics and Child Health (RCPCH) have produced an information toolkit which GPs can use when seeing families of children with a disability, long term or rare medical condition.

The guide – Promoting self care – contains vital information about organisations and resources which will help families manage their child's long-term health and social care needs once they leave the surgery.

Jill Harrison, Contact a Family's External Affairs Director, said: "Research shows that good information empowers parents of children with a disability or rare condition and helps them cope with the challenges they face. Without information the entire family's health and wellbeing suffers."

From next year, already pressured GPs are expected to have knowledge about all kinds of support networks for disabilities and long-term health conditions at their fingertips, in the Information Prescriptions initiative.

This guide will ensure they have the relevant information at hand when seeing families of children with a disabling or rare condition. Promoting Self Care contains information about the best organisations or resources to help families support their child, from time of diagnosis, through to transition to adult services.

Families often don't get the information they need because professionals assume they have already been given the facts from other people. But only 1 in 13 families of disabled children get support from social services.

Chris Verity, Vice President of Education at RCPCH, said: "Health professionals are increasingly under pressure to meet targets and provide a better service. This toolkit will enable GPs to meet their patients' needs and provide the best information to families whose children have a long term health condition or disability."

To download a copy of Promoting Self Care visit [click here](http://www.cafamily.org.uk/papt_selfcare.pdf)
http://www.cafamily.org.uk/papt_selfcare.pdf

Notes to Editors

- Contact a Family is the only UK charity to work with any family of disabled children, whatever the disability or health condition.
- In 2004 RCPCH began working with Contact a Family on a three year project called Parents and Paediatricians Together. The aim was to support health professionals in providing information to families with children who have a long term health condition or disability. As part of the project the Department of Health funded the guide – Promoting Self Care, information for families.
- The National Service Framework for Children and Young People and Maternity Services for England recognises information as important for families. Their standards say parents and young people should be provided with medical, welfare and psychosocial information.
- Information Prescriptions are a new Department of Health initiative being piloted in 20 different health and social care organisations. From 2008, information prescriptions will be given to everyone with a long-term condition or social care need, in consultation with a health or social care professional. Information prescriptions will guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.
- Contact a Family produces a Medical Directory annually, which provides up-to-date and reliable information on a substantial number of disabilities and rare disorders. It contains a medical description of the condition together with details of inheritance patterns and prenatal diagnosis. It also includes information about related support

networks – parent groups, their activities and publications. It is a valuable resource for any professional working with children who have a disability or rare disorder.