

Andrew King

From: Bristol Area Downs Syndrome Support [Bristol_Area_Downs_Syndrome_Supp@mail.vresp.com]
Sent: 01 February 2012 21:45
To: andrew@ahking.freemove.co.uk
Subject: Help needed Community Children's Health Partnership



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Bristol Area Down's Syndrome Support

Care Pathways

Hi,

The Community Children's Health Partnership need help developing their Care Pathway for use in our region. These are the actions that the health professionals will use immediately after a baby is recognised as having Down's syndrome, which will usually be at one of the maternity hospitals.

They would like your comments on the written information and early support given to parents. They would also appreciate your views about when this information is best provided. As you will see below it is not all at once, but for example their experience would conclude that it was best to give parents our details very early, but they are also aware many don't make contact until much later on.

The Care Pathway they propose is:

Parents are to be given the Downs Syndrome Association booklet, 'New Parents Guide'.

Then later on when they are seen by the Community Paediatrician they will be offered the following (either at the first appointment or in stages):

- Parent Held Child Health Record (Red Book) insert for Downs syndrome children
- Early Support Downs Syndrome booklet
- Early Support Family pack (a folder and information relevant to children with special needs)
- Contact details for parent support groups:

BADSS and National DSA
DS Educational Trust - local and national DSMIG

As well as guidance on good practice when sharing news of the diagnosis, there are a range of different people who may be involved in family support - the Family Support Worker (at St Michaels), Community Midwives (particularly if there are early feeding difficulties), Health Visitor and GP, Social worker, Community Paediatrician, therapists, Portage. Offering to put new parents in touch with BADSS, in order to

hear directly from other families, will be done.

At a later stage there may be a plan to write a Family Friendly version of the pathway, including documenting an example of the parents journey and we may be asked to comment on this or even provide suitable example to use.

So if you have an opinion on the actions and information proposed above or can say what impact receiving this information had on you and your family especially in relation to when you got it, they would be very grateful.

In the first instance please provide the information through me. This will help us to improve, as we can see if there is anything we hadn't realised. If you feel you want to say something in confidence to the Community Children's Health Partnership team then I can provide their contact details.

Andrew King
BADSS Secretary
info@BADSS.org.uk

Thank you on behalf of Dr Mary Gainsborough
Consultant Community Paediatrician
Community Children's Health Partnership

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Bristol Area Downs Syndrome Support
7 Jobbins Close
Chipping Sodbury
Bristol, England BS37 6ER
UK



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