## Down syndrome



People with Down syndrome have an extra chromosome (number 21). Because of this they have some shared characteristics and can have a degree of learning difficulties, with appropriate support they are lifelong learners.

Babies will look more like their families than other people with Down syndrome.

Babies with Down syndrome are babies first, with the same needs for love, attention and fun as any other baby.

All children with Down syndrome are individuals, each with their own unique characters and abilities.

This supplement is designed to be used alongside the pregnancy and birth personalised care plan document which aims to support you with decisions along your maternity journey, write your thoughts, wishes and feelings down to enable staff, family and friends to give meaningful support, taking into account what matters to you.

## **Additional information and support**

The <u>Positive about Down Syndrome</u> (<u>PADS</u>) book '<u>Nobody Told Me</u>: <u>The Truth about Down syndrome</u>' is available free of charge from PADS. PADS has closed <u>Facebook parent group</u> to facilitate peer support and a <u>Great Expectations</u> group to support pregnant mums.

<u>Down's Syndrome Association</u> is a national organisation, committed to improving the quality of life of people who have Down syndrome, promoting their right to be included on a full and equal basis with others.

<u>Downright Special</u> is a charity supporting children with Down syndrome in Hull and the East Riding of Yorkshire. It assists families and professionals in all aspects of the care and education of children with Down syndrome. Downright Special has face to face mum and toddler groups and can be contacted to arrange visits for new parents with an antenatal diagnosis of Down syndrome.

## **Antenatal considerations**

These discussions will take place as part of meetings and consultations with health care professionals and support groups. It may take some time for you/your family to reach an informed decision on a way forward.

I have	e a confirmed diagnosis of Down syndrome.				
	As an individual/family a decision has been made to continue this pregnancy and I/we therefore wish to be supported in this journey.				
	As an individual/family, I/we have made a decision not to continue this pregnancy and therefore wish to be supported in this journey.				
My th	oughts, feelings and questions:				
I have	e an increased chance of my baby being born with a diagnosis of Down come.				
	I/we do not wish further screening and prefer to wait until our baby is born for a confirmed diagnosis.				
	I/we wish to have further testing to receive a confirmed diagnosis (testing options will be discussed on an individual basis).				
My th	noughts, feelings and questions:				

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	I/we wish when our baby is born to have some time alone with him/her before a discussion regarding postnatal diagnosis and will let you know when the time is right.				
	I/we wish for staff to be open and honest with us at the birth and wish to discuss diagnosis straight away.				
My thoughts, feelings and questions:					

Many thanks to Positive about Down Syndrome who helped in the production of this HNY LMNS Personalised Care Plan supplementary sheet.