

# Shine's Services



## If you:

- have spina bifida and/or hydrocephalus
- have a child with spina bifida and/or hydrocephalus
- live with or care for someone with these conditions
- are a professional providing support
- are expecting a baby with spina bifida and/or hydrocephalus

**We're here to help.**





## Shine support

Shine plays a leading role in providing specialist support pre-birth and beyond for anyone living with spina bifida, hydrocephalus and associated conditions. We also advise and support parents, families, carers and professional health, and social care staff.

We work on a national level to provide these services through the following specialist service teams:

- Support and Development
- Early intervention
- Health
- Education
- Benefits

Through our regional structure, these teams are accessible in your area and once contacted we will do everything possible to ensure that you receive all the information and support you need.

**To find out more about the support and advice Shine offers visit [shinecharity.org.uk](http://shinecharity.org.uk)**

## Support & Development Workers

Shine employs a team of Support and Development Workers in England, Wales and Northern Ireland. Support and Development Workers are on hand to help you make informed choices.

### The support you really need

Shine's professional Support and Development Workers are here to offer their support, confidential information and advice on:

- Health conditions and treatment
- Staying healthy
- Bowel and bladder issues
- Living independently
- A listening ear

...and much, much more.

Through our Support and Development Workers you will have access to Shine's additional services on Education, Health and Benefits.

**“There are questions you feel too shy to ask, then you realise your Shine Support and Development Worker has heard it all before and has some real answers.”**

**Shine member**

## Health Team

Keeping healthy means individuals and families can spend more time enjoying life. Shine's Health Team has more than 30 years' experience advising on the best options for keeping healthy.

They also understand the worries, concerns, frustrations and possible problems you might face and what you are dealing with.

Advising at NHS clinics, arranging training events for Shine members, providing health information, giving one-to-one advice to individuals, parents, pregnant women, relatives, carers and fellow professionals – are all part of a day's work for the Health Team.

### The Health Team can advise on matters such as:

- Shunts and ETVs (endoscopic third ventriculostomy)
- Bowel and bladder issues
- Skin care
- Tests and treatments for spina bifida or hydrocephalus
- Depression or anxiety
- Effects of ageing
- Orthopaedics
- Sexual health relating to spina bifida or hydrocephalus

### The Health Team can also help:

- With planning a pregnancy – for folic acid advice and how this reduces the chance of spina bifida
- During pregnancy, if you are told your baby has spina bifida, hydrocephalus or anencephaly
- At any time when you or a member of your family gets a diagnosis – whether it is during pregnancy, as a baby, child or as an adult.

## Early Intervention Team

Our early intervention teams in England, Wales and Northern Ireland offer a programme of specialist pro-active support to 0 to 10 year olds and their parent/carers, to ensure that all children with spina bifida/hydrocephalus are given the best start in life and families affected by the conditions are supported to provide the best care for their children.

Our teams coordinate to combine the expertise of our Support and Development Workers, specialist health, education and welfare teams with dedicated early intervention staff to deliver more focussed, concentrated support which includes:

- Emotional support for parents/carers through difficult times
- Practical age-related information to support children's development
- Information on keeping children healthy despite multiple health challenges
- Support to ensure children's educational needs are understood and provided for
- Opportunities to build social connections with other families

## Educational Advisers

Shine's Education Advisers know all about the challenges of getting a good education – from getting your child into the right school, ensuring good support at school to managing changes such as moving from primary to secondary and going to college or university.

Working with parents, children and teachers, the education advisers ensure that the best support is available for children with spina bifida and hydrocephalus. For example, ensuring good access and support for children whose mobility is affected by spina bifida, or that the effects hydrocephalus can have on memory, concentration, organisation and behaviour are recognised so that children can achieve their potential.

## Disability Benefits Advisory Service

Shine's Disability Benefits Advisory Service aims to help more members access key disability benefits.

The service is open to all members and will offer specialist advice and one-to-one support.

Whether you are a parent looking after children with complex needs, a young adult at college, work or setting up home, or someone coping with later in life challenges, the Disability Benefits Advisory Service is here to support you.

### We will:

- Offer one to one support to resolve specific benefit related issues where required
- Support applications to claim appropriate entitlement to benefits
- Offer advice on appealing unsuccessful benefit applications
- Keep up to date with the latest developments in welfare policy and practice





## Get in touch

If you would like to find out more and contact Shine call us on **01733 555988**, email **firstcontact@shinecharity.org.uk** or visit Shine's **website** and fill in a contact Shine form.



**ShineUKCharity**



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**shinecharity.org.uk**



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