

Seminars

Each year the Family Support Workers organise and run seminars to inform and educate service users, parents/carers and also professionals.

To-date topics have included: Spina Bifida, Hydrocephalus, Relationships & Sexuality, Employment, Education, Independence and Social Issues, Transition from Paediatric to Adult Services, Equality & Entitlements, Mobility Training and Awareness Programmes.

Lobbying

Your Family Support Workers are involved in lobbying the government to improve services and access for our service users. Such issues include improved paediatric neurosurgery services, a transition programme to improve communication between paediatric and adult services. We support the research of Folic Acid and run awareness programmes and lobby government for mandatory fortification of Folic Acid in our foods.

Outreach

As a direct response to our service users needs we have run yearly family respite weekends and monthly sports inclusion programmes. For our junior service users we offer summer activity days and day trips.

To-date our monthly support groups, which are run nationally, facilitate first-aid training, peer-to-peer support and study days covering topics such as education, continence management and skin-care management. The agenda for the support groups is led by the needs of our service users.

The FSW team also work as co-ordinators for SHINE (Spina bifida, Hydrocephalus Ireland Nurturing Empowerment) formerly known as Summer Project, Weekend Respite Breaks and the Sports Adventure Week.

We also work closely with our Youth and Respite Services to ensure that the needs of our service users are being met through respite breaks, sports and social events.

Sometimes all that our service users need is someone to listen to them. This is an essential part of the Family Support Workers' role.

We are a confidential*, non-judgemental and respectful service bound by the Data Protection Acts 1998 and 2003.

There are Family Support Workers throughout the country. Please contact the National Resource Centre who will put you in touch with the FSW in your area.



** Confidentiality will not be breached unless a person (service user or otherwise) is deemed to be at risk of or discloses an allegation of sexual abuse, self-harm, suicidal intention or criminal activity. SBHI staff are bound by a duty of care to report such allegations.*

Help Us

SBHI relies on people's generosity so we can support our service users who turn to us for help and advice – people with Hydrocephalus, Spina Bifida, their families and carers. To donate to SBHI please visit www.iasbah.ie or call 01 457 2329.



**SPINA BIFIDA
HYDROCEPHALUS
IRELAND**

Family Support



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Family Support



Family Support Service

Our Family Support Service has been in existence since 2003. We have a network of workers who provide services nationally to individuals with Spina Bifida and/or Hydrocephalus, their families and carers.

The aim of the service is to work with our service users, their families and carers, by providing guidance and information in an environment which is conducive to their needs.

The Family Support Worker (FSW) will visit individuals and/or families in their own home, in hospital, in school or in the work place. The nature and delivery of our service is a direct response to the needs of our service users, their families and carers.

We provide information, support and guidance from the time of diagnosis, which can occur during pregnancy or at the time of birth, through to adulthood. We provide healthcare professionals, education professionals and those working within the disability sector with information, resources and guidance, ensuring that our service users receive the best possible provisions from their multidisciplinary team.

The role of the FSW is very diverse and is guided by the needs of our service users, their families and carers. Our aim is to work with our service users, their families and carers by providing guidance, advocacy, emotional and practical support.

Who are we?

The Family Support Team has people from nursing, education, and social care backgrounds. Our team can assist you by providing information and support on medical matters, youth development, education, continence management, mobility, independent/supportive living, relationships and sexuality, entitlements, employment, advocacy and outreach services.

How can we help?

Medical

Health professionals from midwifery and paediatric hospitals contact us at the time of diagnosis and the FSW team can link up with families in the community to provide information, support and guidance.

We liaise with you and health professionals such as consultants, therapy services, continence and pain management advisors etc.

We offer support and guidance that can empower you to manage your own specific health needs.

Hospital

Your FSW can provide you with a number of different supports while you or your family member is in hospital.

We can visit you in hospital and liaise with your medical team and the hospital social worker.

We offer you support by helping to make sense of 'medical jargon', to ensure you are getting the best possible up-to-date treatment and by empowering you to ask the most relevant questions.

We can also help by sitting with you and talking through your fears and anxieties.

Education

We provide help and support through pre-school, primary, post-primary, resource centre and third-level education by providing information, resources and advice in relation to education supports and provisions.

We also provide training to teachers and special needs assistants, specific to the needs of the individual with Spina Bifida and/or Hydrocephalus.

Housing

We can liaise with you and the appropriate council and government bodies in relation to your housing needs. This may involve guiding you through the process of housing applications, housing adaptation and mobility aids grants, rent allowance or community and residential housing.

Entitlements

There are specific payments that you may be entitled to. We can link you in with the appropriate government bodies and guide you through the application process.

Advocacy

If you would like someone to accompany you to a hospital visit, or to a school review, we would be happy to do so. At other times you may just like to know what your rights are. We are also happy to provide information to schools, colleges, universities, or employers.

Employment

Your FSW can provide you with resources and information on employment.

We can guide you through your work options and put you in touch with the appropriate work and training agencies specific to your needs.

We offer advice on work-place employment and supported employment options and provide information and guidance to your employer and can act as your advocate should you encounter any employment difficulties.

Social Needs

We offer support and guidance on planning for the future, building personal relationships or responding to social barriers that may be encountered.

Your FSW can offer a number of supports in relation to relationships and sexuality. We provide information and guidance and can put you in touch with sexuality advisors.

Continence Management

We have a number of resources and information available on continence management. We can link you in with consultants and community continence advisors.

We also have an in-house continence advisor who offers advice and support on a monthly basis through seminars and phone support.

