



# Understanding Spina Bifida and Hydrocephalus

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Kate Steele, CEO

Sian Prince, Wales Manager



# Who are Shine?



Charity dedicated to providing specialist information, advice and support for hydrocephalus, NPH, spina bifida, anencephaly, and related conditions across England, Wales and Northern Ireland

**Our vision:** A society where all those whose lives are affected by the conditions we support are **empowered** and **enabled** through **choice** and **equality of opportunity**.



[www.shinecharity.org.uk](http://www.shinecharity.org.uk)



# Who Do We Support?



Parents to be



Children, young people and adults living with the conditions



Parents/Carers



Siblings



Professionals



# Our membership across Wales



	0-12	13 - 17	Over 18	Total	Support
Hydrocephalus only	67	26	300	393	Well-being / Lifestyle Health/Clinical Finances Education
Spina Bifida and/ or Hydrocephalus Spina Bifida Occulta	63	29	316	408	Well-being / Lifestyle Health/Clinical Finances Family/carer support
NPH	0	0	29	29	Health/Clinical Well-being / Lifestyle Finances Mobility
Other (Encephalocele; Idiopathic Intracranial Hypertension)	0	2	63	65	Health/Clinical Well-being / Lifestyle Finances
<b>Total</b>	<b>130</b>	<b>57</b>	<b>708</b>	<b>895</b>	

# Shine members with spina bifida and/or hydrocephalus in Mid and West Wales

Total  
Members in  
Wales  
**895**

Carms  
**34**

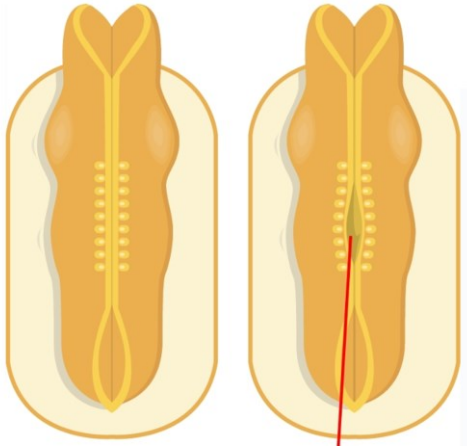
Pembs  
**29**

Powys  
**27**

Ceredigion  
**18**

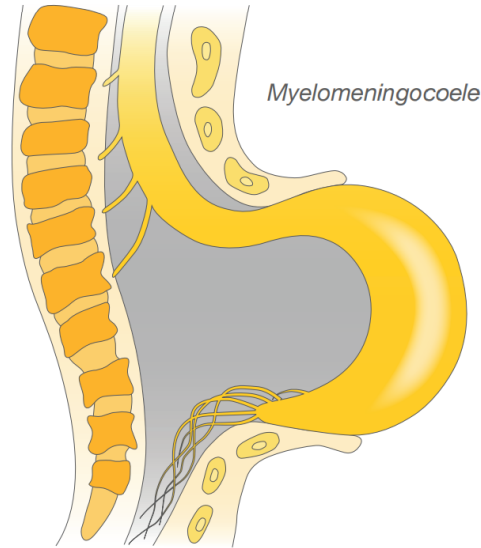
Total  
Members  
Mid and West  
Wales  
**108**

# Neural tube defects



Normal  
neural  
tube  
closure

Spina  
bifida  
lesion



- Gap or split in the neural tube leads to congenital condition e.g. anencephaly or spina bifida
- Fault in the development of either the brain (anencephaly) or spinal cord and surrounding nerves (spina bifida)
- Anencephaly is usually detected at the 12 week scan.
- Spina bifida is often diagnosed during 20 week scan (but not always).
- Many cases of NTDs are potentially preventable with folic acid

# The options for parents-to be at diagnosis



Spina bifida lumbar lesion ultrasound

Postnatal surgery

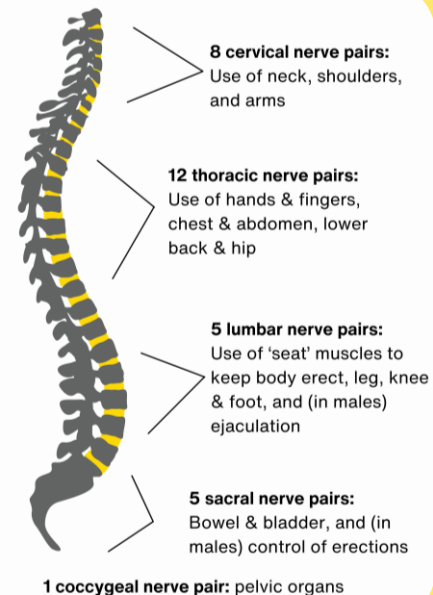
Prenatal surgery

Termination



# How does spina bifida affect people?

Depending where the gap in the spine is and how big it is, different parts of the body might not work quite the same or as well: **everyone is different.**





# How can spina bifida affect people?



**Bladder & bowels**



**Reduced / altered feeling & circulation in lower body**



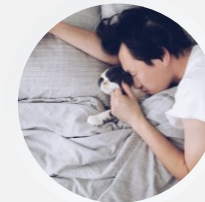
**Mobility & balance**



**Pain**



**Tethered cord**



**Sleep apnoea**



**Weight management**



**Anxiety, depression, self-esteem**



**Thinking, learning, behaviour**

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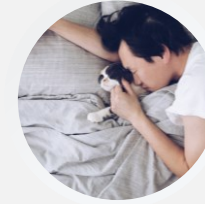
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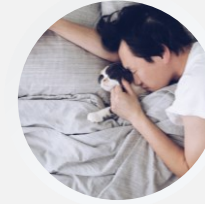
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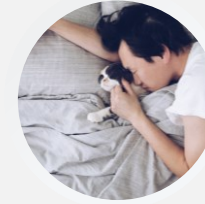
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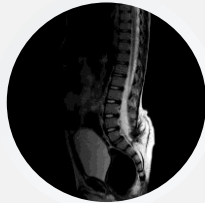
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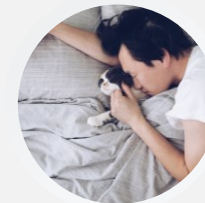
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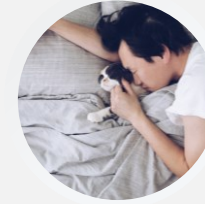
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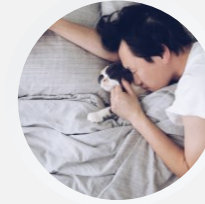
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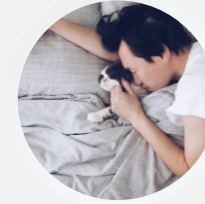
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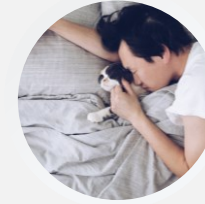
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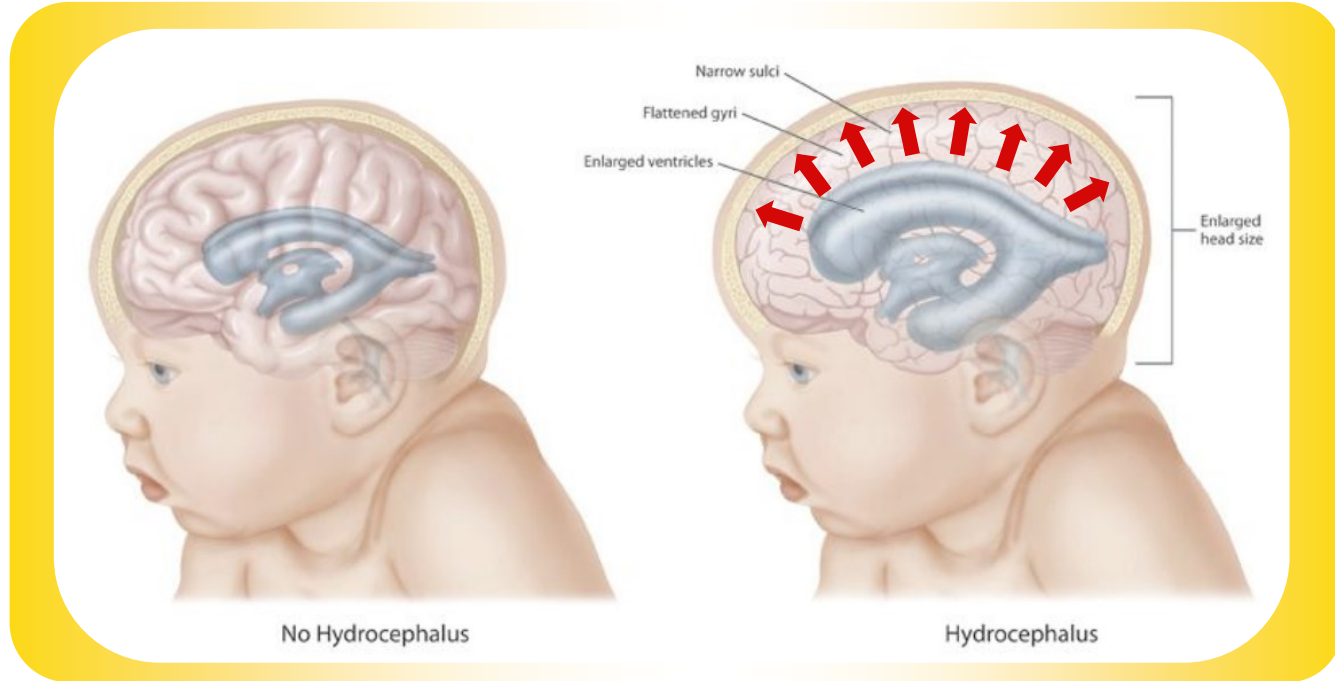
# What is hydrocephalus?

Enlargement of the ventricles causes **compression** of the brain

Typical ventricles



Mikael Häggström,  
M.D. via Wikimedia  
Commons



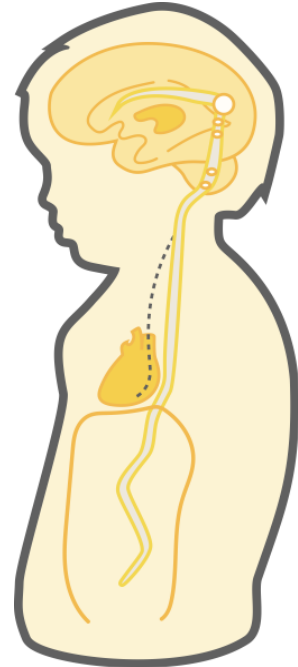
Hydrocephalus



Lucien Monfils via  
Wikimedia Commons

# Hydrocephalus treatments: shunts

- **Shunts** are the most common treatment for hydrocephalus
- CSF is removed from the central nervous system to relieve pressure in the brain.
- CSF is diverted elsewhere in the body (usually the abdomen) to be reabsorbed.
- There are different types of shunt:
  - Ventriculoperitoneal (VP shunt)
  - Ventriculoatrial (VA shunt)
  - Lumboperitoneal (LP shunt)

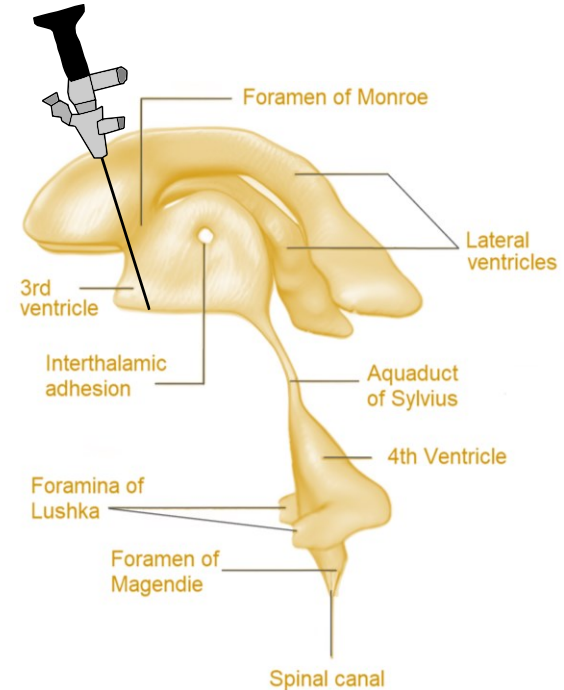


# Hydrocephalus treatment: Endoscopic third ventriculostomy

Drainage hole is made in the floor of the third ventricle to allow the CSF to bypass a blockage

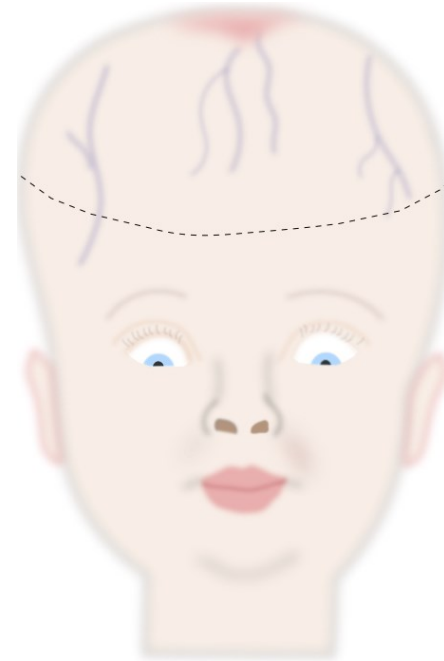
Can be curative

Complications include: damage to other structures of the brain during surgery and healing over of the hole



# Signs & symptoms of acute hydrocephalus: infants

- An unusually large head (macrocephaly)
- Increasing head circumference
- Tense, full, or convex fontanelle
- Prominent / distended scalp veins
- Drowsiness
- Vomiting
- Problems sucking or feeding / failure to thrive
- Irritability
- High-pitched “neuro cry” - crying at a higher and more variable frequency than normal
- Abnormalities in muscle tone (e.g. hypotonia, spasticity) and posture
- Sixth cranial nerve palsy
- Visible sclera above iris of eye ( "sun setting")
- Seizures



# Signs & symptoms of acute hydrocephalus (adults and older children)



**Drowsiness / Confusion**



**Photophobia /  
sensitivity to light**



**Vomiting / nausea**



**Visual disturbances**



**Headache**

# Brain functions & hydrocephalus

**Vital functions:** breathing, heartbeat, swallowing, digestion

**Motor control:** coordinating voluntary movements and balance

**Cognition, Memory, Attention, Language, Executive function**



**Emotions:** regulating and experiencing feelings

**Consciousness:** self awareness, awareness of surroundings

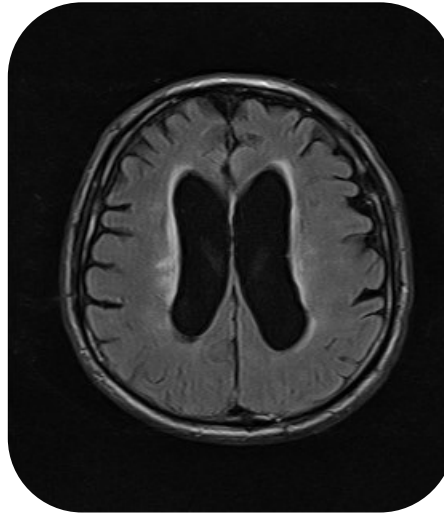
**Sleep regulation:** controlling sleep-wake cycles and patterns

# Normal pressure hydrocephalus

Usually affects people over 60.

Three insidiously developing symptoms: difficulty walking, dementia, urinary incontinence.

Enlarged ventricles, CSF remains at or close to normal pressure.



*Image credit - Nevit Dilmen via Wikimedia Commons*

Enlarged ventricles press on surrounding blood vessels and brain tissue. This can alter the way the brain works.

Shunt treatment can improve, sometimes reverse, symptoms. Not everyone is a candidate.

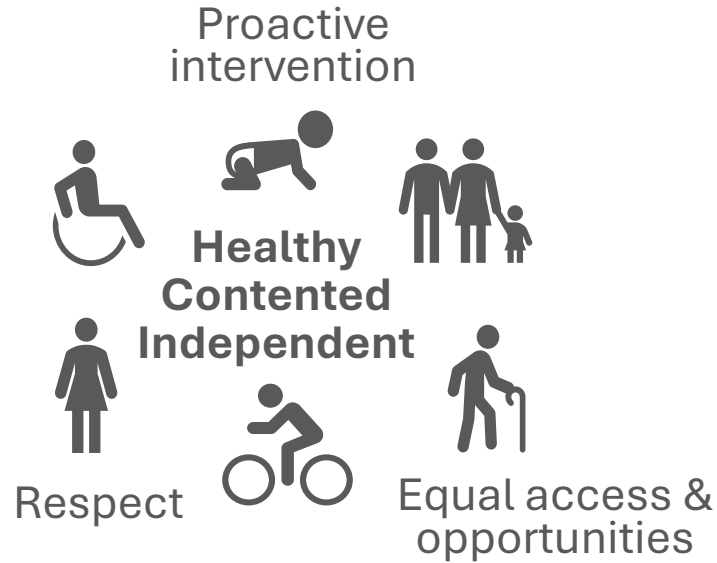
Other interventions needed, e.g. physiotherapy, continence support, pain management



# Parallel Lives – a tale of two teenagers



# What support might someone with spina bifida and/or hydrocephalus or NPH need?



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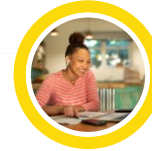
# Our Support



**Resources**  
Specialist



**National & Regional Events**  
Connecting



**Online groups**  
Information & socialising



**Information, Advice  
& Support**  
One to one for all members



**Training and research**  
Raising awareness

# Working with professionals

- Access to specialist information and support
- Attendance or support for clinics
- Resources
- Networks and events
- Research support and engagement
- CPD-accredited learning



# How can you help?

- Understand spina bifida, hydrocephalus, & NPH and what can be done to improve health and well-being
- Remember the importance of folic acid in helping to prevent neural tube defects
- Refer anyone you know to Shine for additional support
- Tell colleagues about us
- Consider working with us to develop care pathways
- Ask us for advice and guidance if you need it
- Become a professional member for regular updates



# For more information, to make a referral, or to join Shine



Call: 01733 555988



Email:  
[firstcontact@shinecharity.org.uk](mailto:firstcontact@shinecharity.org.uk)



Visit our website:  
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# Thank you for listening

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