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Sharing Urological Care & Management:

Guidance from Families and People with Spina Bifida

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GLOSSARY OF ACRONYMS

Acronym	Full
CIC	Clean Intermittent Catheterisation
DMSA	Dimercaptosuccinic Acid
EAU	European Association of Urology
ERN eUROGEN	European Reference Network for Rare Uro-Recto-Genital Diseases and Complex Conditions
ERN ITHACA	European Reference Network for Rare Congenital Malformations and Rare Intellectual Disability
ESPU	European Society for Paediatric Urology
IFSBH	International Federation for Spina Bifida and Hydrocephalus
KUB	Kidneys, ureters and bladder
MRI	Magnetic Resonance Imaging
MACE	Malone anterograde continence enema
NTDs	Neural tube defects
TAI	Transanal Irrigation
VCUG	Voiding Cystourethrogram

1. INTRODUCTION

1.1. Why Guidance from Families and Persons with Spina Bifida?

Being born with spina bifida means starting a lifelong journey of healthcare, learning, adaptation, and personal growth. The individual needs of a person with spina bifida change over time, from diagnosis before or at birth, through childhood and adolescence, and into adulthood. At every stage of life, good healthcare, informed decision-making, and strong partnerships between individuals, families, and healthcare professionals can make a significant difference.

This guidance focuses on one of the most important aspects of lifelong care: urological management. Most people with spina bifida have some degree of bladder dysfunction because the nerves controlling the bladder do not work as expected. Without appropriate management, this can lead to urinary tract infections, bladder complications, and damage to the kidneys, as well as impaired quality of life due to suboptimal continence control. Fortunately, regular monitoring, timely interventions, and person-centred care can prevent many of these complications.

This guidance aims to support families and individuals living with spina bifida by sharing lived experiences of the urological journey across the life course. It brings together insights from parents, caregivers, and people with spina bifida, alongside contributions from healthcare professionals, to offer practical understanding of what to expect at different stages of life and how care can support health, independence, and quality of life.

This guidance is primarily intended for people with spina bifida and their families. It is also relevant for healthcare professionals, patient organisations, and policymakers involved in planning, delivering, or supporting lifelong care.

1.2. What is Spina Bifida?

Spina bifida is a congenital condition, meaning it is present at birth. It develops very early in pregnancy, when the neural tube (the structure that becomes the brain and spinal cord) does not close completely. As a result, the spine and spinal cord do not develop as expected. The condition can affect movement, sensation, bladder and bowel function, and many other aspects of health. Symptoms vary from person to person by type and severity, and can change over time.

Spina bifida is part of a group of conditions called neural tube defects (NTDs), which affect the development of the brain and spinal cord. Other forms include meningocele, closed spinal dysraphism, and spina bifida occulta. Some people have few or no symptoms, while others require lifelong medical support. The level and type of the spinal lesion largely determine how the condition affects an individual.

Many people with spina bifida also have associated conditions, particularly hydrocephalus, in which excess fluid builds up around the brain tissue. Hydrocephalus often requires treatment soon after birth and lifelong monitoring. Other associated conditions, such as Chiari II malformation, may also occur.

The exact cause of spina bifida is not fully understood. It is thought to result from a combination of genetic and environmental factors. Taking folic acid before conception and during early pregnancy significantly reduces the risk of neural tube defects, although not all cases can be prevented.

Several medical terms are used to describe conditions affecting the development of the spine and spinal cord, including neural tube defects (NTDs), spinal dysraphism, and spina bifida. These terms are not always used consistently across countries or medical specialties.

The recommendations in this guidance from families and people with spina bifida encompass the different types of spinal dysraphism falling under ORPHAcode 823 (additional information is available at the Orphanet website www.orpha.net). They may also apply to other forms of spinal dysraphism that present with similar neurological and urological challenges. For readability, the term "spina bifida" is used throughout the document.

1.3. How Common is Spina Bifida?

Spina bifida affects people worldwide. Globally, at least 20 babies per 10,000 live births are born with a neural tube defect (NTD). However, the true number of cases is higher because some affected pregnancies end in miscarriage or termination following prenatal diagnosis.

The prevalence of spina bifida varies by country and region. Differences in access to folic acid supplementation or food fortification, prenatal screening, maternal health, and healthcare services all contribute to these variations. Access to specialist care also differs widely, resulting in significant inequalities in survival, health outcomes, and quality of life.

Improving prevention, ensuring early diagnosis, and providing lifelong multidisciplinary care remain essential to reducing spina bifida's impact worldwide.

1.4. Living with Spina Bifida: The Clinical Perspective

Spina bifida affects each person differently, depending on the level and type of spinal involvement and any associated conditions. It can influence movement, sensation, and the function of several organs and body systems.

A key area of concern in spina bifida is bladder and kidney function. Most people have a neurogenic bladder, meaning the nerves controlling the bladder do not work as expected. This can lead to incomplete bladder emptying, high bladder pressure or leakage. Without appropriate management, this may cause urinary tract infections and long-term kidney damage. Protecting kidney function through regular monitoring and timely intervention is therefore a central goal of lifelong urological care.

Bowel dysfunction is also common and often managed alongside bladder care to support health, continence, and quality of life.

Some people may also experience mobility limitations, orthopaedic complications, or conditions such as hydrocephalus, which can affect learning capabilities and general development options. The severity and combination of these features vary widely between individuals and are relevant when considering urological management.

Because spina bifida is a lifelong condition affecting multiple systems, care is most effective when delivered through a coordinated multidisciplinary approach, with structured follow-up from childhood into adulthood.

1.5. Living with Spina Bifida: The Lived Experience Perspective

Spina bifida is not only a medical condition affecting the bladder, kidneys, and other body systems. It is also a lifelong experience that shapes daily life, general development, and relationships.

For many families, the journey begins at diagnosis (during pregnancy, at birth, or shortly afterwards). This can be an emotionally challenging time. Parents may feel a mix of shock, uncertainty, sadness, and hope, and have unanswered questions. These reactions are natural, and every family responds differently.

As children grow, spina bifida becomes part of everyday life. Families and individuals learn how to manage health needs, including bladder and bowel care, mobility, and regular medical follow-up. Over time, children begin to take part in their own care, building independence and confidence step by step.

Spina bifida also influences education, friendships, and social participation. While some individuals experience significant physical and cognitive challenges, others have fewer limitations. Each person’s experience is unique, and support needs may change over time.

As adolescents and adults, priorities often shift towards independence, relationships, education, employment, sexuality, and future planning. Transition from paediatric to adult healthcare is an important stage, requiring careful preparation to ensure continuity of care and support.

Throughout life, families and individuals consistently highlight the importance of being listened to, having access to clear information, and being supported to make informed decisions. Good care is not only about managing medical needs, but also about enabling participation, autonomy, and quality of life.

Spina bifida is therefore best understood as a lifelong journey, affecting not only the individual, but also their family and wider support network. With appropriate care, information, and support, many people with spina bifida lead fulfilling lives and actively participate in society.

1.6. How this Guidance was Developed

This guidance on the patient journey for spina bifida has been developed from a European patient-centred perspective, led by the International Federation for Spina Bifida and Hydrocephalus (IFSBH), in collaboration with national member associations, people with lived experience, and multidisciplinary healthcare professionals.

Spina bifida representative organisations and individuals living with spina bifida provided contributions, as did clinicians from European Reference Networks including ERN eUROGEN (rare uro-recto-genital diseases and complex conditions), and ERN ITHACA (rare congenital malformations and rare intellectual disability). Additional input was received from members of the European Association of Urology (EAU)/European Society for Paediatric Urology (ESPU) Paediatric Urology Guidelines Panel and the IFSBH Advisory Groups.

The development of this guidance followed a patient journey methodology inspired by the European Reference Networks for rare and complex conditions, integrating clinical expertise, existing evidence, and lived experience.

The aim was to create a practical, person-centred overview of care across the lifespan, with a particular focus on bladder and kidney health in spina bifida.

Relevant key reference frameworks and supporting documents include:

1. ERN ITHACA Patient Journey for Spina Bifida
2. Abrahamson, K., Bogaert, G., Dellenmark-Blom, M., Feitz, W., Goyal, A., & Jouannic, J. M. (2025). EAU–ESPU-ERN eUROGEN-ERN ITHACA–ERN ERKNet-IFSBH Guidelines on spinal dysraphism in children and adolescents. Arnhem (Netherlands): European Association of Urology
3. Dhombres, F., de Saint-Denis, T., Thompson, D., Tahraoui-Bories, J., Lucano, C., Rath, A., ... & ERN network managers Hugon Anne Battye Michelle. (2025). Revised Orphanet nomenclature and classification for spina bifida and other spinal dysraphisms (SBoD). Orphanet Journal of Rare Diseases, 20(1), 348
4. ERN eUROGEN Webinars on YouTube, with special focus on:
    a. ERN eUROGEN Webinar 75: Follow-up in spina bifida/neurogenic bladder in children
    b. ERN eUROGEN Webinar 25: Guidelines on neurogenic bladder and bowel in children and adolescents
    c. ERN eUROGEN Webinar 100: ARM and sexuality
    d. ERN eUROGEN Webinar 11: Intermittent (self-)Catheterisation in children
    e. ERN eUROGEN Webinar 23: Quality of life in patients with ARM
5. Webinar Series for Ukraine: Spinal Dysraphisms (on YouTube EU-Ukraine Webinar Series on Spinal Dysraphisms)

Additional resources:

6. ERN eUROGEN Resources for Anorectal Malformations
7. ERN eUROGEN Clinical Practice Guidelines and Clinical Decision Support Tools
8. ERN eUROGEN Patient Information
9. ERN eUROGEN Transition Guidelines for Rare Uro-Recto-Genital Conditions

2. PATIENT JOURNEY: TIMELINE

The patient journey for spina bifida is lifelong, beginning before birth and extending across all stages of development and adulthood. Each stage brings new medical, functional, and emotional challenges, as well as opportunities for adaptation and independence.

This journey is best navigated through a multidisciplinary, family-centred, and person-centred approach that supports the individual with spina bifida in achieving optimal health, participation, and quality of life.

The table below summarises the key stages of this journey, from prenatal diagnosis to adulthood, highlighting the main medical priorities, family needs, and care coordination. In practice, these stages often overlap, reflecting the continuous and evolving nature of care across the lifespan.

Table 1. A Lifelong Journey Taken One Step At A Time

Stages	Comments
Prenatal Diagnosis	Screening, ultrasound, MRI and, when indicated, amniocentesis help detect spina bifida and associated anomalies. Families may experience shock and uncertainty. Early counselling, clear communication, and referral to spina bifida representative organisations and peer support help parents understand options and prepare for birth and care. It can be very helpful to connect with your local or national spina bifida association and, where possible, talk to other parents who have had a similar experience. Their lived experience can complement medical information and help you understand what life with spina bifida can look like. In selected cases, prenatal surgical repair (fetal surgery) may be an option and can be considered alongside postnatal treatment, including its potential benefits, risks and uncertainties. Depending on the findings, families may also face decisions about continuing or terminating the pregnancy. These are deeply personal decisions. If needed, psychological, social or ethical counselling can provide additional support.
First days of life	Closure of the defect usually in the first 24- 48 hours. Immediate assessment of the spinal lesion and brain (with the help of magnetic resonance imaging (MRI), kidneys, including early kidney and bladder ultrasound (KUB/renal ultrasound) and serum creatinine/cystatin C monitoring. Monitoring for hydrocephalus and associated anomalies is initiated. When postnatal repair is required, prompt surgical closure of the defect is performed. Monitoring of brainstem functions like breathing and heart rate are indicated especially in case of Arnold-Chiari malformation type II. Early multidisciplinary involvement ensures coordinated care. Maintaining parental presence supports bonding and helps families understand early care decisions and follow-up planning. Urological management begins in the first month, with early assessment of bladder function and timely initiation of clean intermittent catheterisation (CIC) when indicated to protect kidney function. In cases of fetal repair, urodynamic evaluation is carried out within the first month.
Usually from 2-6 months of age	Ongoing kidney and bladder monitoring, including ultrasound and renal function tests. Urodynamic studies are repeated as indicated based on clinical findings and risk profile.

	Bladder management is adjusted, including CIC and/or anticholinergic medication when required, based on bladder dynamics and renal protection needs. In the first months there is a tendency towards having bowel movements very frequently, which irritate the skin around the anus. Proper skin barrier treatment is often indicated. Parents continue to receive structured training and support in daily bladder and bowel care.
6-12 months of age	Continued kidney and bladder monitoring, including ultrasound and renal function checks. Urodynamic studies are repeated when clinically indicated to assess bladder pressures and risk to the kidneys. Bladder and bowel management are adjusted based on individual needs, including optimisation of CIC and medication where required. Physiotherapy, early developmental support, and orthopaedic follow-up continue. Families are supported in integrating daily care routines into everyday life, with increasing confidence and independence in caregiving.
1-5 years, infancy and early years including kindergarten	Continued kidney and bladder monitoring, including regular ultrasound and renal function checks. Urodynamic studies are performed when indicated to guide bladder management and protect renal health. Bladder and bowel management is maintained and adjusted as the child grows. Where appropriate, children are gradually involved in their own care, including early participation in CIC under supervision. Bowel management programmes are introduced or optimised to support continence, comfort, and participation in daily activities. Physiotherapy, mobility support, and orthopaedic follow-up continue. Early education and inclusive childcare settings support social development and participation. Families are supported in balancing medical care with normal childhood development, fostering confidence and reducing care burden over time.
5-11 years, school aged children	Ongoing medical monitoring and surgical reassessment and intervention, as needed. Focus on bowel management and gradual development of self-care skills. Collaboration with schools and therapists promotes inclusion and independence, while supporting emotional wellbeing and quality of life. Where available and appropriate, a neuropsychological assessment can help identify areas of cognitive strength and areas where additional support may be needed. This information can help families and teachers adapt learning strategies to the child's individual needs. Children are supported, where appropriate, in gradually developing independence in CIC and bowel management, including transanal irrigation (TAI) or a Malone anterograde continence enema (MACE). If bladder management with CIC is not sufficient or is not possible, additional treatments or surgical options may be considered, such as botulinum toxin injections into the bladder or, in selected cases, a temporary vesicostomy.
11-18 years, adolescence to adulthood (transition)	Medical follow-up continues, including renal, bladder, and orthopaedic assessments. Transition planning for adult care is introduced and progressively strengthened during this period. Puberty and physical development bring important changes for all genders, which may influence bladder function, continence, and long-term kidney health. These

	changes require ongoing monitoring and timely adjustment of bladder and bowel management to maintain health and prevent complications. During adolescence, young people are encouraged and supported to develop increasing self-management skills and autonomy, including bladder and bowel management and, where appropriate, self-catheterisation. Privacy, dignity, and access to a safe and comfortable space for catheterisation are important for confidence and independence. The level of independence can develop according to each young person's abilities and support needs, alongside participation in social, educational, and daily life activities. Open and age-appropriate conversations about self-catheterisation and other aspects of self-care can help reduce embarrassment and make these routines feel like a normal part of everyday life. If CIC is difficult, insufficient, or no longer suitable, other treatment options may be considered according to the individual situation. These can include botulinum toxin injections into the bladder wall and, in selected cases, surgical options such as a temporary vesicostomy, a continent catheterisable stoma with bladder augmentation, or an incontinent urinary diversion. Adolescence can also be a period where engagement with long-term treatment may fluctuate. Supportive, youth-friendly services and structured transition programmes are essential to maintain continuity of care and help young people stay connected to their health management. Open and age-appropriate conversations about self-catheterisation and other aspects of self-care can help reduce embarrassment and make these routines feel like a normal part of everyday life. A structured transition process can support a safe and coordinated move to adult services, adapted to the needs and level of independence of each young person.
From 18 years to the end of life	Lifelong monitoring of kidney and bladder function, continence management, and prevention of complications continues throughout adulthood. Transfer to adult healthcare services takes place in a structured and individualised way, depending on the needs of the person with spina bifida and, where appropriate, the caregivers. This transition is planned in advance to ensure continuity of care and avoid gaps in follow-up. Adults focus on independent living, education, employment, relationships, and social participation. Access to specialist adult services and peer networks supports autonomy, health, and quality of life. Having access to a private, safe, and comfortable space to carry out catheterisation can support dignity, confidence, and independence, going beyond physical accessibility alone.

3. STAGE 1: PRENATAL AND BIRTH

3.1. The Need for Family-Centred Care

When a child or loved one is diagnosed with spina bifida, families often experience a wide range of emotions, including fear, uncertainty, hope, and confusion. Many of us who have lived this journey understand how overwhelming the early stages can feel.

What we have learned is that caring for spina bifida requires more than medical treatment. It requires partnership, communication, and support that includes the whole family. Experience shows that outcomes improve when families are active partners in care, not just recipients of information.

Family-centred care means families are informed, heard, and respected at every stage. It strengthens trust, supports decision-making, and helps families feel more confident and less alone.

Spina bifida is a lifelong condition, and families need both emotional support and practical guidance to navigate the journey ahead. One of the most valuable things we have experienced is clear and transparent communication. As families, we need to understand what is happening, not just today, but in the future too. Honest conversations about surgeries, possible complications, and long-term needs help us make informed decisions. We value healthcare professionals who speak openly with us and give us time to process information and ask questions.

Another key part of this journey is managing expectations. Knowing what to expect, whether related to walking, learning, or bladder and bowel care, helps us prepare, set realistic goals, and avoid unnecessary stress. Hearing difficult news is not always easy, but understanding the full picture has helped us plan better and find hope in small, meaningful steps.

As discharge approaches, parents must be prepared to care for their child at home. This means hands-on training in essential care tasks, particularly urological and bowel management, which often begins in infancy. Confidence in catheterisation techniques, hygiene practices, and knowing when to seek medical advice can reduce anxiety and prevent complications.

This is also the time to introduce families to the broader care team, including community nurses, physiotherapists, occupational therapists, and medical specialists, who will support the child and family through different stages of life. Connection with spina bifida associations and peer networks can provide additional reassurance, helping families feel less alone as they navigate the months and years ahead.

Hospitals caring for babies with spina bifida benefit from having a structured, long-term care pathway in place. Lifelong care does not mean constant crisis; it means stable, coordinated support that allows families to focus on helping their child thrive.

Spina bifida affects the entire family, not just the person diagnosed. It can be emotionally and financially challenging. Access to counselling, peer support, and respite services can ease the burden and prevent caregiver burnout, and, most importantly, they help families feel seen, supported, and reminded that they are never alone on this journey.

3.2. First Information and Questions

Receiving the first information that your child may have spina bifida is often one of the most challenging moments for any family. Whether the diagnosis comes during pregnancy or immediately after birth, parents are suddenly faced with complex medical terms, urgent decisions, and deep emotional uncertainty.

Clear, compassionate communication at this stage is essential. Families need time, space, and support to understand what spina bifida means, what treatments are possible, and what the future might hold. Every family's journey begins differently; some receive early diagnosis and counselling, while others learn about the condition after delivery. In all cases, information is most helpful when delivered with honesty, sensitivity, hope, and realistic expectations, as much as possible at that time point, since future developments can be difficult to predict.

Common questions at this stage include:

- What is spina bifida, and what does it mean for my child?
- What kind of surgery or treatment will be needed, and when?
- Is prenatal (fetal) surgery an option in my case, and what are the potential benefits and risks?
- Will my child be able to walk, learn, or live independently?
- What are the risks of complications, and how are they managed?
- Who will coordinate our care and guide us through next steps?
- Where can we find support from other families or associations?

Families can ask as many questions as they wish and request repeated explanations when needed. Written materials, diagrams, and access to patient support organisations can make a significant difference in helping families absorb and process information during such an emotional time.

Early involvement of a specialist multidisciplinary team can support coordinated communication and continuity of care from the beginning. A coordinating paediatrician or paediatric neurologist, together with a coordinating nurse specialist, can help bring together neurosurgery, neonatology, genetics and genetic counselling, urology, orthopaedics, rehabilitation, nursing, social work, psychology, and other relevant professionals involved in the child's care.

Connecting families early with peer support networks and parent organisations can also provide reassurance. Many families find it helpful to hear from others who have lived through similar experiences and to understand that, although the journey can be complex, children and adults with spina bifida can live meaningful and fulfilling lives.

> ***Example #1:*** *"Doctors sometimes avoid discussing the risk of seizures in order not to increase stress for the family. However, a sudden seizure can have much more serious consequences - both emotionally for parents and for the child's development. Therefore, open and timely information is an important part of preparing a family. When seizures happened for the first time, we did not immediately understand what was going on, lost valuable time, and as a result ended up in intensive care. If doctors informed parents in advance about the possibility of seizures and at least explained what they are and how they may manifest, parents would be much better prepared. I believe that if a child has a risk of seizures, parents should have clear instructions on what to do and, upon a doctor's recommendation, a basic emergency kit with the necessary medication."* ***Mother of a 4-year-old girl with spina bifida, Ukraine***

3.3. Immediate Care After Birth

When a baby is born with an open form of spina bifida (such as myelomeningocele), the first hours and days are critical. The goals of care during this time are to protect the exposed spinal cord, prevent infection, stabilise the baby's condition, and prepare for surgery.

Parents are often introduced to several specialists within a short period (which can feel overwhelming). Clear communication, emotional support, and coordinated care are therefore essential from the very beginning.

3.3.1 Prenatal Diagnosis and Decision-Making

Spina bifida is often diagnosed during pregnancy through routine ultrasound screening and, when needed, further imaging such as fetal MRI. This early diagnosis allows time for families to receive counselling, understand the condition, and prepare for the birth and care of their baby.

At this stage, families may face important and very complex decisions. These can include decisions about continuing or terminating the pregnancy and, in some settings, consideration of prenatal (fetal) surgical repair when this option is available and clinically appropriate.

Prenatal (fetal) surgery is offered only in very selected cases in specialised centres and is not suitable for all pregnancies. Families benefit from balanced, evidence-based information about potential benefits, risks, and uncertainties, and are supported in making informed decisions without pressure.

In situations where time for decision-making is limited, families benefit from a 360-degree approach to counselling, including clear medical information, psychosocial support, and, where desired, the opportunity to speak with other families who have lived through similar experiences. Peer perspectives can offer valuable insight into everyday life with spina bifida, complement clinical information, and support informed, values-based decision-making.

Regardless of the chosen path, clear communication, emotional care, and connection to multidisciplinary teams and spina bifida organisations can provide important support throughout the journey.

3.3.2 Immediate Clinical Priorities

After birth, care typically takes place in a neonatal intensive care unit or specialised surgical centre.

Early care focuses on stabilisation, protection of the spinal lesion, and coordinated assessment to guide urgent treatment and longer-term management.

Key early priorities include:

- Protection of the spinal lesion: The exposed area is covered with a sterile, moist dressing to prevent infection and further damage.
- Positioning: The baby is kept on their side or stomach to avoid pressure on the lesion.
- Infection prevention and stabilisation: Antibiotic prophylaxis and temperature regulation are started promptly.
- Early neurological monitoring: Head circumference is measured regularly, and cranial ultrasound is performed to assess for hydrocephalus.
- Early multi-system assessment: Early neurological, urological, and orthopaedic evaluation guides short- and long-term management.
- Early evaluation of autonomic function (breathing, heart rate), especially in cases of Arnold-Chiari malformation type II.

Early multidisciplinary assessment may also guide further investigations when clinically indicated, including renal and bladder ultrasound, blood tests (including renal function), and additional imaging such as spinal or brain MRI. Voiding cystourethrogram (VCUG) may be performed in selected cases to assess lower urinary tract function. If vesical-urethral reflux is suspected, videocystometry, if available, may provide the best information on reflux timing and the success of therapeutic interventions.

Early surgical closure of the spinal defect is typically performed within the first 24-48 hours after birth to reduce infection risk and support neurological protection. Breastfeeding or bottle feeding support can include guidance on positioning and bowel movement tips for babies with limited lower body movement.

If hydrocephalus is present, treatment such as a ventriculoperitoneal shunt or alternative cerebrospinal fluid diversion procedure may be required during the same hospital admission or later, depending on clinical evolution.

Following surgery, some babies require monitoring or recovery in a neonatal intensive care unit or intensive care setting, depending on their clinical condition and local protocols.

3.3.3 Multidisciplinary Coordination

Spina bifida care requires a multidisciplinary approach from the very beginning. The newborn's care team usually includes:

- Neonatologist/Paediatrician: overall coordination and medical stabilisation
- Neurosurgeon: surgical closure of the spinal lesion, management of hydrocephalus, and ongoing neurosurgical follow-up
- Urologist: early bladder assessment and initial guidance on kidney protection
- Orthopaedic specialist: examination of lower limb deformities and spine
- Rehabilitation team (physiotherapy, occupational therapy and related disciplines): positioning, early movement, prevention of contractures, functional development, and parent training
- Nursing and wound care: ensuring infection prevention and early family education
- Social worker/psychologist: providing emotional and logistical support to families

Ideally, a care coordinator or spina bifida specialist nurse can act as the family's main point of contact, ensuring continuity of information, arranging follow-up, and helping navigate appointments.

Access to coordinated, multidisciplinary care varies across European countries. In some settings, families may not be automatically referred to a structured care pathway or supported by a coordinated team.

In such cases, families often need to take a proactive role in seeking information, identifying specialists, and coordinating care themselves. Being well informed and asking questions can help ensure the child receives appropriate, timely support. Information may also be available through national spina bifida representative organisations, the IFSBH, and the websites and webinars of the European Reference Networks, which connect patient representatives with specialist teams at hospitals across Europe.

A clinical geneticist may be involved when there are associated anomalies or suspicion of a syndromic condition requiring further diagnostic evaluation.

3.3.4 Family Support and Communication

Parents must be given space and time to bond with their baby and to ask questions about upcoming procedures. Consistent medical explanations across the care team can help avoid confusion and reduce anxiety.

Clear communication includes:

- Explaining the diagnosis, surgery, and expected recovery in understandable terms;
- Preparing families for the appearance of the surgical site and wound care;
- Providing written and visual information (booklets, leaflets, diagrams);
- Encouraging parents to participate in care (e.g., gentle handling, comforting, early caregiving tasks).

Hospitals can facilitate parental presence in the neonatal unit and allow family participation in daily care routines whenever possible. Even during intensive medical care, bonding is possible and vital, through touch, voice, and eye contact.

3.3.5 Preparing for Discharge

Once surgery and early recovery are complete, parents will begin learning to care for their child at home. Education before discharge can include:

- Wound care and hygiene;
- Bladder management (recognising urinary symptoms, understanding bladder emptying, and early training in clean intermittent catheterisation when indicated);
- Bowel care routines;
- Physiotherapy and positioning techniques;
- Signs that require medical attention (fever, vomiting, shunt symptoms, wound changes).

Families can leave the hospital with:

- A clear discharge plan and list of upcoming appointments;
- Written information summarising the diagnosis, surgery, and contact details of the multidisciplinary team;
- Referral to a spina bifida clinic or follow-up centre for coordinated care;
- Contact information for local or national spina bifida associations for peer support and information.

Before going home, parents can benefit from having a clear understanding of their baby's condition and know where to turn for help.

In some contexts, including parts of Europe, families receive very severe prognoses about a child's future, sometimes alongside informal suggestions to place the child in institutional care. Balanced, evidence-based communication, avoiding definitive predictions about future abilities, and respecting family autonomy are important when discussing the child's future and care options.

The first months after discharge are a time of learning and adjustment, but also one of bonding and adaptation, as families gradually build confidence and experience their child's development and potential.

3.4. Early Infancy and First Months (Post-Surgical and Home Care)

The period after returning home from hospital marks the beginning of daily life with spina bifida. It can be both joyful and challenging; families are learning new routines while caring for their baby's healing, comfort, and development.

During this stage, regular follow-up with the multidisciplinary team is essential to monitor healing, prevent complications, and lay the foundation for long-term health and independence.

3.4.1 Follow-up and Medical Monitoring

After surgery, the baby's recovery continues under the guidance of several specialists. Regular follow-up visits assess neurological, urological, and orthopaedic status.

Key elements of early monitoring include:

- Surgical site review: to ensure proper healing and detect infection or leakage;
- Head circumference and fontanelle monitoring: to detect signs of hydrocephalus or shunt malfunction;
- Brain imaging (cranial ultrasound or MRI as indicated): for ongoing evaluation of ventricular size and Chiari II malformation and spinal developments and for the very selected cases of fetal surgery for further outcome evaluation of the procedure;
- Renal and bladder monitoring: including ultrasound every 3–6 months and urodynamic studies to evaluate bladder function and kidney function with the help of a DMSA or MAGIII scan;
- Orthopaedic assessment: to monitor hip stability, foot position, early spinal alignment, and support for stability and mobility.

Findings can be recorded in a shared care plan accessible to parents and healthcare providers, ensuring continuity between hospital and community care.

3.4.2 Bladder and Bowel Movement

Protecting kidney function is a key priority from infancy onward.

CIC must be introduced early as part of a proactive bladder management approach. It is often started soon after surgical repair of open spina bifida, depending on individual clinical assessment and local protocols. In many cases, CIC is initiated before full urodynamic evaluation when there is a high suspicion of neurogenic bladder dysfunction, with ongoing reassessment over time.

Antibiotic prophylaxis may be used in selected cases to reduce the risk of urinary tract infections.

Bowel management begins with observing bowel habits and using early supportive strategies such as positioning, stimulation, and dietary guidance.

Families can be reassured that bladder, and bowel care can become a normal part of daily life, and that most children and families adapt well over time.

3.4.3 Mobility, Physiotherapy, and Development

Early physiotherapy supports healthy muscle tone, posture, and movement. A physiotherapist helps parents learn exercises and positions to encourage:

- Flexibility and strength in the legs and hips;
- Proper alignment and prevention of contractures;
- Safe handling and carrying techniques;
- Supported sitting and early weight-bearing (using standing frames if indicated).

Assistive devices such as orthoses, standing frames, or mobility aids such as wheelchairs may be introduced gradually depending on the child's needs.

Occupational therapy can support the development of fine motor skills and play, functional independence, helping the child progress at their own pace.

3.4.4 Nutrition, Growth, and General Health

Infants with spina bifida have the same nutritional needs as other children, although feeding may occasionally be affected by neurological or gastrointestinal factors.

Breastfeeding or bottle-feeding support can include guidance on positioning when lower-limb movement is limited.

Regular growth monitoring helps ensure adequate nutrition and early identification of feeding difficulties.

Vaccinations generally follow national schedules unless otherwise medically indicated.

Families can be supported in establishing daily routines that promote comfort, bonding, and development through feeding, play, and sleep.

3.4.5 Emotional Support and Family Adjustment

Caring for a baby with spina bifida is a major adjustment. Many parents describe the first months at home as a time of both love and uncertainty.

Families benefit greatly from:

- Accessible psychological support (individual or family counselling);
- Peer support groups and parent mentors;
- Open communication with the care team, especially for addressing fears about future development or surgeries.

It is important for families to know that progress often comes in small steps, and that every achievement – a healed wound, a successful catheterisation, a smile – is meaningful.

3.4.6 Coordination of Care and Community Resources

Each child can benefit from having a designated care coordinator (such as a specialist nurse or rehabilitation physician) responsible for:

- Scheduling follow-up appointments;
- Sharing reports among specialists;
- Linking families to community and rehabilitation services;

- Facilitating access to medical equipment and home adaptations.

Families can also be introduced to local early intervention services, which can provide physiotherapy, developmental assessments, and family education close to home.

National and regional spina bifida associations provide additional support through peer networks, practical guidance, advocacy, and community engagement.

4. STAGE 2: THE FIRST YEAR

The first year of life for a baby with spina bifida is a critical period for recovery, growth, and establishing routines that support long-term health and development. Multidisciplinary follow-up is essential to monitor neurological, urological, and orthopaedic health, support early development, and empower families in daily care.

4.1. Early Infancy (0–3 months)

In the first weeks, babies recover from spinal closure surgery and, if needed, cerebrospinal fluid shunting. Care focuses on monitoring the spine, brain, and kidneys, preventing infection, and supporting general health, including feeding, growth, and vaccinations. Parents are introduced to daily care routines, including gentle handling, positioning, and monitoring for warning signs such as fever, irritability, or wound changes.

Families are encouraged to maintain parental presence in the neonatal unit, fostering bonding and supporting the baby's emotional well-being. Clear, compassionate communication from healthcare professionals helps parents understand their child's condition, the surgical plan, and the follow-up schedule.

Parent-to-Parent Tips

- Observe your baby carefully and report any unusual changes promptly. Keep a diary of feeding, medications, and wound care, and note questions to ask different health care providers.
- Monitor head circumference regularly, as rapid increases or abnormal changes require prompt medical evaluation. Early detection may help prevent complications.
- While washing your baby, observe and take note of their urination pattern. Check the pads regularly: if you notice any changes, such as pads that were previously soaked becoming dry, take note of this. Any such changes should be reported to your healthcare provider promptly.

Recommendation: Early connection with patient organisations and peer support networks is a key enabler of improved parental confidence, emotional wellbeing, and long-term engagement in care.

Example #2: *"Looking back, I'm very glad we started catheterisation from the newborn stage. My baby was not even one month old when I was trained. Even though CIC is considered standard, there are still doctors in Europe who don't recommend it, which is unfortunate. The earlier it becomes part of daily life, the less stressful it is for both the family and the child."* ***Mother of a 12-year-old girl with spina bifida, Bulgaria***

Example #3: *"When my child was born, I felt completely lost. The hospital gave me medical information, but I still didn't understand what daily life would look like. Meeting other families through the national Spina Bifida Association changed everything. They shared practical advice, but most importantly, they gave me hope. Seeing older children and young adults living full lives helped me realise that my child could have a future beyond my fears."* ***Mother of a child with spina bifida, Italy***

Example #4: *"When we finally returned home after the surgery and a long hospital stay, we had a very important realisation: despite all the diagnoses and medical challenges, she is, first and foremost, our child. Our baby girl was only a month old, and what she needed most of all was love, hugs, and a happy childhood. Over time, you realise that a serious diagnosis or disability should not stand in the way of a full life and a happy family. As soon as we stopped focusing on the illness and just started living, we found so much more strength to keep moving forward."* ***Mother of an 11-year-old girl with spina bifida, Ukraine***

4.2. Infancy (3–6 months)

During this stage, attention continues on bladder and kidney protection alongside developmental progress.

CIC and medication such as anticholinergics may be adjusted based on ongoing assessment. Regular follow-up with ultrasound and, when indicated, urodynamic studies supports prevention of urinary tract complications and protection of kidney function.

Orthopaedic assessment and physiotherapy continue to support posture, movement, and early motor development.

Parents gradually gain confidence in daily care routines, including catheterisation, positioning, and supportive exercises.

Parent-to-Parent Tips

- Practice CIC under supervision until confident; consistency reduces infection risk;
- If you do not feel confident with CIC after training with specialist nurses, let your nurse or urologist know;
- Everyone progresses at a different pace – some feel comfortable from the first attempt, others need more time;
- If you need additional time or extra sessions, do not hesitate to ask for support;
- Position your baby correctly during physiotherapy and daily care;
- Keep a diary of catheterisation, bowel routines, and therapy sessions.

Example #5: *"When the child was six months old, once the wound had healed and the hydrocephalus had stabilised, it seemed that the hardest part was behind us. However, a sudden fever brought anxiety back into our family. We later learned it was caused by urinary retention. At that time, we were not informed about potential complications involving the kidneys and urinary system. It took about a year to find the right specialists, complete the necessary examinations, and start clean intermittent catheterisation. Looking back, we realise much of this could have been done sooner with timely information and guidance. It is clear: monitoring the kidneys and bladder must be a priority from a child's very first days."* ***Mother of an 11-year-old girl with spina bifida, Ukraine***

4.3. Later Infancy (6–12 months)

During the second half of the first year, developmental milestones such as rolling, supported sitting, reaching for objects, and early exploration become increasingly important.

Bladder and bowel management continue to be closely monitored and adapted as the child grows. Regular follow-up supports kidney protection, neurological development, and orthopaedic alignment, with care adjusted according to individual needs.

European Reference Networks
Funded by the European Union

Physiotherapy and occupational therapy support early mobility, posture, and functional development. Mobility aids such as supportive seating or orthoses may be introduced where appropriate.

Families are encouraged to continue practising routines with confidence, involving all caregivers whenever possible. Early social interaction and play support cognitive and emotional development, while peer support and spina bifida organisations provide practical guidance and reassurance throughout this stage.

Parent-to-Parent Tips

- Celebrate small developmental milestones; it helps build confidence and morale;
- Maintain predictable routines but adapt to your child's needs;
- Communicate openly with the multidisciplinary team; early reporting prevents complications;
- Take short breaks and seek support to reduce stress.

Example #6: *"I had promised myself that my son would walk. I took him to every possible therapy and rehabilitation session. My days were filled with appointments and specialists. By the end of his first year, I felt devastated when I saw other children his age starting to stand and take their first steps, while he struggled in my arms. He never learned to walk, despite all the efforts. Over time, I came to understand and accept this. He is an amazing young man. Looking back, I sometimes regret that in those early years we didn't spend more time simply playing and enjoying each other. Rehabilitation is important, but it is not everything, and it should not become everything in a family's life."* ***Mother of a young adult with spina bifida, Bulgaria***

Example #7: *"Once we mastered the bladder and bowel management techniques, they quickly became a regular routine. There is less anxiety now and less psychological discomfort caused by incontinence. The most important things are professional support, patience, and family teamwork."* ***Mother of a 9-year-old girl with spina bifida, Ukraine***

5. STAGE 3: INFANCY AND EARLY CHILDHOOD (1–5 YEARS)

From ages 1 to 5, children with spina bifida continue to grow, develop new skills, and gradually gain independence. Care during this stage focuses on maintaining health, supporting motor and cognitive development, and preparing for school and social participation. Families continue to play a central role, working closely with the multidisciplinary team to ensure coordinated, holistic care.

5.1. Early Childhood (1–2 Years)

During this stage, the emphasis remains on bladder and bowel management, orthopaedic care, and physical development. CIC routines are reinforced and adapted as the child grows. Regular follow-up of kidney and bladder health is essential and may include ultrasound and, when indicated, urodynamic testing and blood tests to support early detection of complications. Parents continue to monitor for signs of urinary tract infections or complications and maintain contact with urology specialists as needed. Equally important, especially in cases of recurrent urinary tract infections, is appropriate bowel management such as enemas, laxatives, or MACE.

Orthopaedic follow-up assesses hips, spine, and lower limbs, and physiotherapy supports muscle strength, posture, and early mobility as much as possible in each case. Families are encouraged to incorporate daily exercises into playtime to make therapy enjoyable for the child.

Social and cognitive development becomes a focus. Encouraging exploration, communication, and early problem-solving helps lay the foundation for learning. Families are guided on how to create stimulating and safe environments that promote curiosity and independence.

Parent-to-Parent Tips

- Make exercises and mobility practice part of daily play;
- Keep a simple diary of catheterisation, bowel routines, and therapies;
- Encourage self-care in small steps, such as helping with dressing or toileting, even if partially.

Example #8: *"We were fortunate to work with a very skilled therapist who helped us understand how important the early years are for building lifelong skills. Therapy was focused on functional independence, dressing, feeding, sitting, and moving safely. From an early age, we also encouraged our daughter to be involved in her catheterisation routine in simple ways, like undressing herself or handing over the lubricant. Step by step, this helped her feel confident and prepared for the moment when she could try it on her own. Looking back, this focus on functionality made a big difference in her independence and quality of life."* ***Mother of an 18-year-old young woman with spina bifida, Bulgaria***

Example #9: *"We can say with confidence: any communication with specialists who see the child as a person rather than just a diagnosis has a powerful therapeutic effect. This is not just medical care - it's an important factor in social adaptation. Over time, we understood that interactions during doctor visits, rehabilitation, and even the journey to the medical institution are all part of a child's social experience. When specialists work toward improving quality of life, the child learns to interact with the world and feels more confident."* ***Mother of an 11-year-old girl with spina bifida, Ukraine***

5.2. Mid-Early Childhood (2–3 Years)

Between ages 2 and 3, children continue developing gross and fine motor skills. Physiotherapy and occupational therapy support walking (when possible), balance, and coordination. Mobility aids such as wheelchairs, orthoses, or adaptive equipment may be introduced or adjusted to match developmental needs.

Bladder and bowel routines continue, with gradual encouragement of independence where possible. Families work closely with healthcare providers to review urological management and make any necessary adjustments.

Cognitive and social skills develop rapidly. Playgroups and early childhood education provide opportunities for socialisation, communication, and emotional growth. Families are supported in preparing their child for a structured learning environment while maintaining consistent routines at home.

Parent-to-Parent Tips

- Encourage your child to participate in toileting or dressing routines;
- Celebrate small milestones, like walking a few steps with support when possible or learning new words;
- Introduce your child gradually to group activities to build confidence and social skills.

5.3. Later Early Childhood (3–5 Years)

This stage increasingly focuses on preparing for school entry and promoting independence in daily routines.

By ages 3–5, children are preparing to enter school. Care continues to focus on medical monitoring, mobility, independence, and school readiness. Regular follow-ups with urology, orthopaedics, and neurosurgery ensure ongoing health and early identification of complications. Physiotherapy continues to support mobility, while occupational therapy helps with fine motor skills, self-care, and adaptive strategies.

Families increasingly focus on preparing the child for school (whenever possible), including communication with teachers, arranging necessary support, and ensuring an inclusive learning environment. Encouraging autonomy in daily routines, like self-catheterisation or toileting with supervision and continence care if needed, builds confidence and independence. Sometimes special schools are needed to have access to health care support during the day.

Emotional wellbeing is also central. Children develop self-awareness, social relationships, and a sense of agency, while parents continue to receive guidance, peer support, and reassurance from patient organisations.

Parent-to-Parent Tips

- Practice school-related routines, such as managing clothing, toileting, and carrying equipment;
- Support early independence while supervising to ensure safety (when possible);
- Keep a log of medical visits, therapy sessions, and milestones to communicate effectively with teachers and healthcare providers.

Example #10: *"My daughter was three years old when she first started using a wheelchair. She was so young, and so happy to have that independence. I have never regretted introducing it early. It allowed her to play with other children in parks and playgrounds and be part of their world. Accessibility in our city was, and still is, a challenge, with stairs and curbs making things difficult. But despite this, I am glad we made that decision early, because it gave her more freedom and confidence."* ***Mother of a 12-year-old girl with spina bifida, Bulgaria***

Example #11: *Before medical appointments, it can be helpful to write down questions and concerns in advance. Being informed and prepared helps families take an active role in discussions with healthcare professionals. Open communication and shared decision-making with the care team are key to ensuring the best possible support for the child."* ***Mother of an 11-year-old girl with spina bifida, Ukraine***

6. STAGE 4: SCHOOL AGE (5–11 YEARS)

Between the ages of 5 and 11, children with spina bifida continue to develop independence, engage in formal education when possible, and strengthen social and cognitive skills. This stage emphasises maintaining health, supporting learning, promoting mobility, and fostering self-confidence, while preparing children for more self-management of their care.

6.1. Early School Age (5–7 Years)

At the beginning of school, children adapt to a structured learning environment. Medical care continues with regular follow-up for urology, orthopaedics, and neurosurgery. Bladder and bowel management routines are well established, and children may begin to take a more active role in their care under supervision.

Physiotherapy and occupational therapy focus on gross and fine motor skills, posture, and mobility to support independence in school and daily activities. Early literacy, numeracy, and cognitive skills are supported in collaboration with teachers and therapists.

Parent-to-Parent Tips

- Encourage your child to participate in self-care routines like catheterisation and toileting with guidance;
- Communicate openly with teachers about your child's needs and abilities;
- Support participation in social and physical activities, including a variety of sports where possible, not only swimming;
- Encourage a healthy and balanced lifestyle, including regular movement and attention to diet, to help prevent inactivity and excess weight gain;
- Maintain a routine at home that mirrors school expectations to reinforce consistency.

Example #12: *"My daughter learned to self-catheterise relatively late; she was around 11 or 12. However, from an early age, all the important people around her knew how to support her: both grandmothers, her grandfather, her cousin, and her assistant at school. We made sure they were properly trained, and this helped her stay independent in daily life even before she could do it herself. She did not have to depend only on me, I was able to work, and she could follow her own routine. Having a supportive family and people who were willing to learn made a huge difference for her independence and confidence."* ***Mother of a young woman with spina bifida, Bulgaria***

6.2. Mid School Age (7–9 Years)

Between ages 7 and 9, children are refining skills in self-management, social interaction, and physical abilities. Multidisciplinary care continues to monitor bladder and bowel function, orthopaedic needs, mobility, and neurological health. Adjustments to mobility aids, wheelchairs or orthoses may be required as the child grows. Particular attention to spinal alignment and early signs of scoliosis can help identify changes that may require further assessment.

Cognitive and social development becomes increasingly important. Participation in group activities, sports, and hobbies fosters confidence and peer relationships. Families support learning and daily routines, helping children balance independence with safety.

Parent-to-Parent Tips

- Encourage participation in social and physical activities appropriate for your child's abilities;
- Monitor and support school assignments while fostering self-reliance;
- Keep a simple log of health, therapy, and school progress to support communication with teachers and healthcare providers.

Example #13: *"I still remember the first time I entered a wheelchair basketball hall. I was amazed. These older players were moving so fast, turning, spinning, controlling their chairs while dribbling; it felt like magic. I told myself that one day I wanted to be like them. Ten years later, I can say that I've learned that magic too. It wasn't easy. Training was three times a week, late in the evening, and my father would always wait for me, because he knew how much it meant to me. Through sport, I met young men with different disabilities who were living independently, working, and succeeding in life. That was incredibly important for me. I found role models, and I found friends."* ***Young man living with spina bifida, Bulgaria***

6.3. Later School Age (9–11 Years)

In the final years before adolescence, children increasingly take responsibility for parts of their health routines, including bladder and bowel management, continence care, mobility exercises, and daily care tasks. Regular medical follow-up continues to prevent complications and ensure early intervention when needed.

Children are encouraged to develop problem-solving skills, self-advocacy, and participation in care-related decision-making. School readiness for transition to adolescence includes fostering independence, resilience, and confidence in social and learning environments when possible.

Parent-to-Parent Tips

- Gradually allow your child to manage more aspects of daily care independently;
- Support engagement in hobbies, sports, and social activities while monitoring safety;
- Introduce age-appropriate education on body awareness, boundaries, and personal safety, including prevention of abuse;
- Work closely with teachers and therapists to anticipate needs as your child grows.

Example #14: *"When my daughter was 9, I started a new job and could no longer go to school to catheterise her. She had to learn quickly to do it on her own. I had always been very strict about hygiene, especially because she had frequent infections when she was younger. At the beginning, she would forget steps, washing her hands, using disinfectant, or closing the lubricant properly. We argued a lot, and I was very worried that she wouldn't manage. It was a difficult time, but I had to trust her. She kept telling me, 'Don't worry, Mom, I'll manage.' And she did. Maybe it wasn't perfect according to my standards, but she became independent. In the first months I was very anxious about infections, and there were a few over the years, but not as many as I had feared."* ***Mother of a girl with spina bifida, Bulgaria***

Example #15: *"We can say with confidence: any communication with specialists who see the child as a person rather than just a diagnosis has a powerful therapeutic effect. This is not just medical care – it's an important factor in social adaptation. Over time, we understood that interactions during doctor visits, rehabilitation, and even the journey to the medical institution are all part of a child's social experience. When specialists work toward improving quality of life, the child learns to interact with the world and feels more confident."* ***Mother of an 11-year-old girl with spina bifida, Ukraine***

Example #16: *"The experience of families shows that an excessive number of surgeries, prolonged hospital stays, emotional exhaustion, and financial burden can significantly impact the quality of life for both the child and the entire family. It is important for parents to have a realistic understanding of the diagnosis, and the role of doctors in this process is key. Specialists can help families avoid focusing solely on physical recovery or achieving a particular functional result at any cost. At the same time, it is important to maintain a balance between medical interventions and resources dedicated to the child's socialisation, education, and development of interaction with the world."* ***Mother of an 11-year-old girl with spina bifida, Ukraine***

7. STAGE 5: ADOLESCENCE TO ADULTHOOD (11–18 YEARS, TRANSITION)

During adolescence, children with spina bifida experience significant physical, cognitive, and social changes. This stage focuses on gradually increasing independence, maintaining health, and preparing for adult life and adult healthcare services. Families, healthcare professionals, and educators continue to play a key role in supporting self-confidence, self-management, and participation in daily life.

7.1. Early Adolescence (11–14 Years)

In early adolescence, regular follow-up continues across urology, nephrology, orthopaedics, neurosurgery, and rehabilitation. Bladder and bowel management routines are usually well established, and adolescents begin to take more responsibility for daily care such as catheterisation and continence care if needed, medication, and mobility routines, with ongoing parental support.

Puberty brings important physical and emotional changes. Adolescents and families may have questions about body development, continence changes, fertility, relationships, and sexual health. Information can be introduced in an age-appropriate and respectful way, adapted to cognitive level and individual needs.

Social identity, peer relationships, and self-esteem become increasingly important. Emotional wellbeing can include attention to anxiety, body image, and confidence in social participation.

Structured opportunities for peer interaction, including patient camps, group activities, and early peer support programmes, can support identity formation, reduce feelings of isolation, and strengthen confidence.

Parent-to-Parent Tips

- Encourage your adolescent to take an active role in their care, gradually reducing supervision as appropriate;
- Support participation in social, recreational, and school activities to build confidence;
- Ensure access to age-appropriate information about body changes, relationships, sexual health, and personal safety;
- Maintain open communication about health, emotions, and practical challenges.

Example #17: *"I was very worried about my daughter's first menstruation, especially how we would manage catheterisation at the same time. In reality, it was not as difficult as I had imagined. We simply pay extra attention to hygiene during those days. I have noticed that she sometimes has more difficulty holding urine during her period, but we have learned how to manage it. Over time, it became just another part of our routine."* ***Mother of a girl with spina bifida, Bulgaria***

Example #18: *"I started catheterising myself at the age of eight at school, with my mother there to support me. I have always used a drainage bag because I never felt comfortable catheterising directly into the toilet. At first, I was very hesitant to try other options, but with my parents' support I gradually realised that I could manage it myself. Over time, I found the method that worked best for me, and I now feel comfortable and independent with catheterisation. Being able to do it myself is very satisfying and has given me a greater sense of autonomy."* ***Young woman with spina bifida, Spain***

Example #19: *"Managing catheterisation in my daily life has not been particularly difficult for me, including during my studies and while practising sport. However, it can sometimes be inconvenient, especially when I have to find a suitable and clean place or interrupt time with friends or family to use the bathroom. During adolescence, I felt more embarrassed and tried to hide it from my friends. As I grew older, I became more comfortable talking about it and realised that it was simply part of my routine. With time and experience, I have developed habits that make catheterisation and hygiene easier to manage in everyday life. Menstruation requires some extra attention to hygiene, particularly to avoid staining the catheter, but it also becomes easier with experience."* ***Young woman with spina bifida, Spain***

7.2. Mid Adolescence (14–16 Years)

Between ages 14 and 16, the focus shifts further towards autonomy, preparing for transition to adult care, and promoting self-management. Adolescents are encouraged to take responsibility for catheterisation, continence care, bowel routines, medications, and scheduling appointments, while continuing regular multidisciplinary care follow-up.

A key challenge during this stage is reduced adherence to long-term treatments, including CIC and medications such as anticholinergics. This may be linked to treatment fatigue, busy daily schedules, or the wish for greater independence. Open, non-judgemental communication is essential to maintain engagement and protect long-term kidney health.

Some adolescents may reduce fluid intake to limit urinary leakage or decrease the frequency of catheterisation. While understandable, this can increase the risk of urinary tract infections and long-term renal damage. Information and support around adequate hydration can help young people understand its role in bladder and kidney protection.

Structured opportunities for peer interaction, including patient camps, group programmes, and peer mentoring, can support adherence, reinforce self-management skills, and provide realistic role models for independent living. These experiences may also help adolescents normalise their condition and reduce feelings of isolation during a period of increasing autonomy. When medication becomes difficult to manage or does not provide sufficient control, other treatment options, such as botulinum toxin injections into the bladder, may be considered where available and clinically appropriate.

At the same time, adolescents develop greater awareness of their medical history and begin to communicate more directly with healthcare providers. Vocational guidance and discussions about future education, work, and independent living may also begin.

Parent-to-Parent Tips

- Allow your adolescent to manage tasks independently while providing guidance when needed;
- Encourage them to ask questions and understand their health care plan;
- Support the development of organizational skills to manage appointments, treatment routines, and school or social commitments.

Example #20: *"My parents were very worried that my classmates would find out that I catheterise. It was something seen as embarrassing, something to keep secret. Because of that, I didn't go to sleepovers or school camps. In high school, I shared it with my best friend, and nothing bad happened. Little by little, I became more open, and I realised that people didn't care as much as I had imagined. Looking back, I believe that the fewer taboos we have around these topics, the better it is for young people."* ***Young woman living with spina bifida, Bulgaria***

7.3. Late Adolescence (16–18 Years)

In late adolescence, the main focus is preparing for transfer to adult healthcare services and strengthening full independence. Adolescents work closely with the multidisciplinary team to ensure a smooth transfer from paediatric to adult care, including urology, neurosurgery (if applicable), orthopaedics, and rehabilitation services.

This transition period can be vulnerable, with an increased risk of reduced follow-up or interruption in care. Transition planning is most effective when it does not rely on young people or families finding adult specialists on their own. Before transfer, an adult care team or appropriate referral pathway can be identified, together with a named point of contact or care coordinator where possible. A shared transition plan and direct handover of relevant clinical information can support continuity of urological, neurological, orthopaedic, rehabilitation, and other ongoing care needs. The goal is continuity of care rather than simply transferring responsibility from one service to another.

In addition to medical care, life skills become increasingly important, including managing education or employment pathways, transport, personal organisation, finances, and social relationships. Emotional support remains important, and peer networks or mentorship can provide reassurance during this period of change.

In some situations, bladder or bowel management may become difficult to maintain or may no longer provide adequate control. Additional interventions may then be considered to protect kidney health, improve continence, or support quality of life. Depending on the individual situation, these may include surgical options such as a colostomy or an ileal conduit. Clear communication between the individual and the multidisciplinary team can support understanding of the options, benefits, risks, and implications for everyday life.

Parent-to-Parent Tips

- Encourage adolescents to take the lead in medical appointments and decision-making;
- Support independent living skills gradually, balancing safety and autonomy;
- Continue to provide emotional support and maintain connections with peer and patient networks;
- Ensure a clear and structured transition plan to adult services is in place before transfer.

Example #21: *"To stay dry, I need to take medication three times a day and catheterise every three hours, and it has been like this for years. When I was younger, my parents reminded me, but over time it became my responsibility. I know I'm old enough to manage it, but for some reason I still forget. I've tried setting alarms, but my routine changes, or I turn them off and move on without thinking. I've also tried leaving reminders and keeping my medication close, but when I'm out, it doesn't always work. It's not that I don't understand how important it is; it's just hard to stay consistent. When I miss my medication for a couple of days, I start having leakage, and that's often what leads to tension at home."* ***Teenage girl living with spina bifida, Bulgaria***

Example #22: *"The transition from paediatric to adult care is very challenging. This year my daughter turns 18, and we started early to look for specialists and make choices. In our case, the process is not well structured, so we had to navigate it on our own. I am grateful that some of her paediatric doctors agreed to continue following her, because the condition is rare and it is not easy to find experienced specialists. We attend appointments together, but I encourage her to speak about her condition herself. Sometimes she even manages to book her own appointments. They are growing up, and they need to get used to taking the lead."* ***Mother of a young woman with spina bifida, Bulgaria***

8. STAGE 6: ADULTHOOD AND LIFELONG CARE (18 YEARS AND BEYOND)

Adulthood for individuals with spina bifida is characterised by increasing independence, self-management, and full participation in society, including education, work, relationships, and community life. Lifelong care remains essential to maintain physical health, prevent complications, support autonomy, wellbeing, and quality of life.

Adult life can also involve changes in health, mobility, bladder and bowel function, pain, fatigue, or other support needs. Access to appropriate healthcare, social support, assistive products, personal assistance, education and employment opportunities can help people participate in daily life according to their abilities, preferences, and circumstances.

Employment is an important part of participation, but not everyone can work full-time or in the same way throughout life. Where needed, information about social protection, disability benefits, reasonable accommodations, vocational support, and other community resources can help people navigate changing circumstances.

8.1. Medical Monitoring and Health Maintenance

Access to coordinated multidisciplinary adult care can support long-term health and continuity of care. Where available, an adult multidisciplinary clinic with spina bifida experience can bring together relevant specialists. Where such a clinic is not available, a clearly coordinated network of specialists can provide continuity, with defined follow-up responsibilities and an accessible route back to specialist care when needs or health circumstances change. This is particularly important in settings where expertise in spina bifida is concentrated in paediatric services.

Regular follow-up with healthcare professionals remains essential to prevent complications, even when individuals feel well.

Urological care remains central. Regular renal and bladder monitoring, including ultrasound, blood tests, and urodynamic evaluation when indicated, helps preserve kidney function and detect changes early. Adults usually manage bladder and bowel routines independently but may need periodic adjustments to their care plan over time.

Orthopaedic care focuses on monitoring spine, hips, and lower limbs. Changes in mobility, posture, pain, or function may require adjustment of orthoses, mobility aids or wheelchairs, or rehabilitation strategies.

Neurological and general health monitoring includes assessment of neurological status, chronic pain, fatigue, skin integrity, and other long-term complications that may evolve with age.

Consistent follow-up matters even during stable periods, as subtle changes in bladder pattern, mobility, or energy levels may indicate early complications.

> ***Example #23:*** *"Attending multidisciplinary clinic visits has often felt taxing and frustrating, especially when I don't feel fully understood or that my needs are being met, but I continue to show up because these visits play an important role in my care. Over time, I've learned to communicate my concerns more clearly, recognising that consistent follow-up helps build a baseline for continuity of care and allows early detection of issues before they become serious or irreversible as I age with spina bifida. I've also come to understand that even subtle changes - such as increased fatigue, shifts in bladder patterns, or small differences in mobility - can be significant, and documenting these over time helps my care team identify the most appropriate management strategies to support my independence for as long as possible."*
> ***Woman with spina bifida, member of the IF Adult WG SBH***

8.2. Independence and Daily Life

Adulthood can bring increasing opportunities for self-management, autonomy, and participation in education, employment, relationships, and community life. The highest possible level of self-management and autonomy can be supported according to each person's abilities, preferences, and support needs. Independence does not necessarily mean doing everything without assistance; it can also mean having choice and control over how and when support is provided, including through supported decision-making where needed.

Practical aspects of independent living can include:

- Managing healthcare, appointments, medications, bladder and bowel routines, and other aspects of personal care, with support where needed;
- Using mobility aids or a wheelchair, assistive products, and adaptive equipment in ways that support participation and independence;
- Accessing accessible transport, toilets, and other facilities, including managing catheterisation and bowel routines outside the home;
- Planning and carrying supplies discreetly when travelling, studying, working, or participating in social activities;
- Developing strategies for managing fatigue, pain, and changes in health while maintaining daily activities and participation;
- Organising personal assistance or other support when needed;
- Knowing what to do and who to contact when usual bladder, bowel, mobility, or healthcare routines are disrupted;
- Developing practical strategies for education, employment, finances, relationships, travel, and community participation.

Family, peer, and community support may remain important throughout life, particularly during transitions or periods of health change. The type and level of support can change over time according to the person's circumstances, preferences, and needs.

Parent/Peer-to-Peer Tips

- Encourage independence while remaining available for guidance or support when needed;
- Keep a personal health record to track appointments, treatments, and key changes;
- Stay connected with spina bifida associations or support networks for advice and shared experience.

Example #24 *"Growing up, I was always supported by my parents, but at some point I realised I needed to take control of my own care. Participating in activities organised by the association, especially camps and group experiences, helped me gain confidence and learn from others like me. It was the first time I saw independence not as something scary, but as something possible."* ***Young adult living with spina bifida, Italy***

Example #25: *"As I've gotten older, I've experienced increasing joint and musculoskeletal issues -aches, pain, and reduced flexibility and mobility - which felt like a wake-up call. It motivated me to take a more active role in my health by making small dietary changes, exploring supplements, and committing time and effort to supervised exercises I once thought were beyond me, and over time, I've experienced meaningful improvements in myself."* ***Woman with spina bifida, member of the IF Adult WG SBH***

Example #26: *"Flexibility and creativity in managing clean self-catheterisation is essential, as it can be stressful at workplaces or social event venues lacking accessibility. While I carry my little bag filled with all my essential items around, I often remind myself to keep an open mind and ignore the stares and comments, because I deserve to live my best life, even though the world may not understand my invisible challenge. For many years, my journey felt quite lonely as I learned to manage changes in my condition through trial and error on my own. Discovering our national association a few years ago was a turning point – it brought a sense of joy and excitement, and for the first time, I connected with others, made friends, and could share tips and exchange experiences with people who truly understand."* ***Woman with spina bifida, member of the IF Adult WG SBH***

8.3. Social Participation and Relationships

Adults with spina bifida can lead fulfilling lives, including relationships, higher education, and work and leisure activities. Inclusive environments, accessible infrastructure, and supportive policies can enable participation in society.

Relationships, intimacy, sexuality, and fertility can be important aspects of adult life. Concerns about continence, catheterisation, body image, privacy, sexual function, fertility, pregnancy or disclosure of spina bifida to a partner may affect confidence and relationships. Fear of rejection or uncertainty about how to discuss spina bifida can also be part of these experiences.

Respectful, non-judgemental information and support can help adults explore these topics according to their individual circumstances and preferences. This can include opportunities to discuss sexual health and fertility with healthcare professionals, practical advice on managing continence and catheterisation during intimate relationships, information about available treatments or reproductive options, and psychological or peer support when concerns about body image, confidence, relationships, or disclosure arise.

Privacy and dignity remain important in intimate relationships and in everyday life. Access to appropriate spaces and equipment, the ability to manage bladder and bowel care discreetly, and having the freedom to decide what, when, and how much to disclose can support confidence and autonomy.

Psychosocial wellbeing remains important throughout adulthood. Counselling, peer networks, mentorship, and opportunities to connect with others with lived experience can provide additional support during changes in relationships, employment, health, or other aspects of adult life.

Example #27: *"I'd love to see the world, but travel for me depends on having a supportive and understanding companion who can help if health issues or unexpected "accidents" arise. I have to carefully consider accessibility, pacing, and travel duration, and it takes a lot of mental and emotional preparation. Still, it's possible - I have some walking ability, and with perseverance in managing fatigue, aches, and unforeseen challenges, I can make it work."* ***Woman with Spina bifida, member of the IF Adult WG SBH***

8.4. Lifelong Planning and Advocacy

Lifelong planning includes vocational goals, independent living arrangements, and long-term health care organisation. Adults are encouraged to take an active role in advocating for their needs and ensuring continuity of care.

Parent/Peer-to-Peer Tips

- Set realistic goals for education, employment, and personal development;
- Actively seek accessible services and community resources;
- Maintain a proactive approach to health monitoring and prevention of complications;
- Engage in shared decision-making with healthcare providers;
- Keep informed on new innovations and interact with patient organisations or their communications.

Example #28: ***"****Keeping a periodic catheterisation log and a bowel management schedule helps parents monitor the child's condition and provides the doctor with important data for the timely detection of infection risks, evaluation of kidney function, and adjustment of treatment. As the child grows, it is necessary to update the catheter size, the type of irrigation systems, and medication dosages in a timely manner. This approach helps maintain a stable health condition and improves the child's quality of life."* ***Mother of an 11-year-old girl with spina bifida, Ukraine***

Example #29: *"I grew up thinking that my impairment would prevent me from being a mother. At some of the international meetings organised by the IFSBH, I met many women with SB who gave birth and realised it is possible for me, as well. However, as gynaecologists are usually not aware of pregnancy in women with SB, I had to share information on increased folic acid intake and family planning with my doctor, but she was open to listening to me and offered her support. Now, I know it is possible and that I could plan it in the future."* ***Woman with Spina Bifida, 34***

8.5. Mental Health and Emotional Wellbeing

Living with spina bifida can have a significant emotional and psychological impact across the lifespan, for individuals and their families. While many people adapt well and lead fulfilling lives, they may also experience periods of stress, anxiety, low mood, or emotional fatigue, particularly during times of transition such as adolescence, surgery, or changes in health status.

Mental health is an integral part of routine care, not a separate or secondary issue. Regular opportunities to discuss emotional wellbeing can be included in follow-up visits, alongside physical health monitoring. Where additional support is needed, clear pathways to appropriate psychological or mental health services can help ensure timely access to care.

Common challenges may include coping with chronic medical routines, concerns about continence, body image, pain or fatigue, social inclusion, and the transition to adult care. The emotional impact of managing a lifelong condition can vary over time. Families and caregivers may also experience long-term stress, uncertainty, and burnout.

Access to psychological support, when needed, can be available throughout life. This may include counselling, clinical psychology, peer support, or group-based interventions. Peer networks and spina bifida associations can play an important complementary role by reducing isolation, normalising shared experiences, and providing opportunities to connect with others who have lived experience. Peer support can complement, but does not replace, professional psychological or mental health support when this is needed.

Protective factors include stable routines, supportive family and social environments, inclusive education and work settings, and opportunities for autonomy and participation. Strengthening self-management skills, maintaining meaningful social connections, and having access to peer and professional support can contribute to resilience and quality of life.

> ***Example #30:*** *"For me, CIC was introduced later in childhood, and I was doing it independently through a catheterizable stoma channel since I was 13. However, as my health status changed when I was 33, doctors recommended me to start CIC through urethra, and that shift was challenging both physically and emotionally. Therefore, as my urologist recommended me to see psychologist to help me overcome the shock, I started psychotherapy, and it was extremely important. She guided me to accept the situation and regain self-confidence, which was really helpful in starting new patterns and feeling comfortable in social situations".* ***Woman with Spina Bifida, 34***

9. ANNEX

9.1. International and European Organisations

- **European Association of Urology (EAU):** The European professional organisation representing urology specialists. Its guidelines and educational resources cover urological conditions, including neuro-urology and the management of bladder dysfunction. https://uroweb.org/

- **ERN eUROGEN:** European Reference Network for rare uro-recto-genital diseases and complex conditions. Its patient information section includes resources specifically on spina bifida, including a Patient Journey. https://eurogen-ern.eu/

- **ERN ITHACA:** European Reference Network for congenital malformations and neurodevelopmental disorders. Its resources include the Spina Bifida Patient Journey and clinical guidelines. https://ern-ithaca.eu/

- **ERN ERKNet:** European Reference Network for rare kidney diseases, including patient information relevant to spinal dysraphism and kidney health. http://erknet.org/

- **European Society for Paediatric Urology (ESPU):** A specialist society within the EAU focusing on paediatric urology. It promotes education, research and improved standards of care for children with urological conditions, including bladder dysfunction associated with spina bifida. https://www.espu.org/

  International Federation for Spina Bifida and Hydrocephalus (IFSBH): The international representative organisation for spina bifida and hydrocephalus. You can obtain information, resources, and links to spina bifida organisations around the world. Website: www.ifglobal.org

9.2. Guidelines and Clinical Resources

- **Guidelines on Spinal Dysraphism in Children and Adolescents**: Developed jointly by the European Association of Urology (EAU), European Society for Paediatric Urology (ESPU), ERN eUROGEN, ERN ITHACA, ERN ERKNet, and IFSBH. The guideline covers multidisciplinary assessment, urological management, kidney and bladder health, and long-term follow-up. See also: https://uroweb.org/guidelines/paediatric-urology/chapter/spinal-dysraphism-in-children-and-adolescents-formally-neurogenic-bladder

- **ERN eUROGEN Patient Information:** includes patient journeys, information sheets, videos and other resources developed with patients and clinicians. See also https://eurogen-ern.eu/for-patients/patient-information/

- **ERN ITHACA Patient Journeys:** patient-focused guides designed to help people and families understand the clinical pathway and participate in care decisions. See also: https://ern-ithaca.eu/guidelines/patient-journeys/

9.3. National Support: List of European Spina Bifida Associations

1. **Austria**: Spina Bifida und Hydrocephalus Österreich (SB&HÖ), www.sbho.at
2. **Belgium:** Vlaamse Vereniging voor Spina Bifida en Hydrocephalus vzw (VSH), www.spinabifida.be/
3. **Bulgaria**: Spina Bifida and Hydrocephalus-Bulgaria (SBHB), www.sbhb.org/
4. **Croatia**: Udruga osoba i roditelja djece sa spinom bifidom "Aurora"
5. **Cyprus**: Pan-Cyprian Association of Rare Genetic Diseases 'Unique Smiles', https://monadikaxamogela.org/
6. **Denmark:** Rygmarvsbroksforeningen af 1988, www.rmb-1988.dk/
7. **Estonia**: MTÜ Eesti Seljaajusonga ja Vesipeahaigete Selts, www.kelluke.ee/
8. **Finland**: Suomen CP-liitto ry, www.cp-liitto.fi/
9. **France**: A.S.B.H. Association Nationale Spina Bifida et Handicaps Associés, https://ifglobal.org/members/france-asbh/
10. **Georgia**: Georgian Spina Bifida Association Facebook /
11. **Germany**: Arbeitsgemeinschaft Spina Bifida und Hydrocephalus e.V. Bundesverband (ASBH), https://asbh.de/
12. **Hungary**: Spina Bifida and Hydrocephalus section of MEOSZ, www.meosz.hu/
13. **Ireland**: Spina Bifida Hydrocephalus Ireland (SBHI), www.sbhi.ie/
14. **Italy**: Associazione Spina Bifida Italia (ASBI), www.spinabifidaitalia.it/
15. **Latvia:** Latvijas spina bifida un hidrocefālijas biedrība (LSBH), http://spinabifidalv.webs.com/
16. **Lithuania**: Spina Bifida ir Hidrocefalija asociacija, www.sbh.lt/
17. **Luxembourg**: Association pour le Spina Bifida, www.spina-bifida.lu/
18. **Norway**: Ryggmargsbrokk- og hydrocephalusforeningen www.rh-foreningen.no
19. **Poland**: SPINA Foundation, https://spina.com.pl/
20. **Portugal:** Associação Spina Bifida e Hidrocefalia de Portugal, www.asbihp.pt/
21. **Romania**: Asociația Română de Spina Bifidă și Hidrocefalie https://www.facebook.com/ARSBH/
22. **Scotland**: Spina Bifida Hydrocephalus Scotland https://www.sbhscotland.org.uk/
23. **Serbia:** Spina Bifida and Hydrocephalus association of Serbia https://hisbas.rs/
24. **Slovakia**: Slovenská spoločnosť pre spina bifida a/alebo hydrocefalus, o.z., www.sbah.sk/
25. **Spain:** Federación Española de Asociaciones de Espina Bífida e Hidrocefalia (FEBHI) https://febhi.org/
26. **Sweden**: Rörelsehindrade Barn & Ungdomar, https://rbu.se/
27. **Switzerland**: Spina Bifida und Hydrocephalus Schweiz www.spina-hydro.ch
28. **The Netherlands**: SBH Nederland, https://sbhnederland.nl/
29. **UK:** SHINE Charity http://www.shinecharity.org.uk/ / Harry's Hat www.harrys-hat.org
30. **Ukraine:** Parents Association for Spina Bifida and Hydrocephalus 'Lights of Spirit' https://lightsofspirit.org/

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