

spina bifida

Introduction

Spina bifida: key primary care issues

**Spina bifida is a static congenital neural tube disorder resulting in continuing evolving disease involving multiple organ systems. Those affected require lifelong surveillance with coordinated management involving the patient, parents, general practitioners, neurologists, physiotherapists, occupational therapists, social workers, nurses, neurosurgeons, urologists, orthopaedic surgeons, physicians and other health professionals.*

**The term spina bifida is used throughout this manual to refer to all myelodysplasias unless specifically stated. Similarly, issues specific to hydrocephalus alone will be highlighted, although many of the issues relating to spina bifida are relevant.*

Key issues for clinicians

- Spina bifida is one of the most severe congenital abnormalities compatible with a full and active life.
- Active surveillance to diagnose problems early is more likely to keep a person with spina bifida active and independent.
- Routine surveillance must involve regular review of the neurological, urological and musculoskeletal systems.
- Changes in neurological signs can indicate severe, treatable underlying pathology. Clinicians need to have a record of past neurological signs for a clear comparison in any ongoing neurological review.
- All new neurological signs require immediate referral to a specialist centre.
- Urological complications are a major cause of morbidity and mortality in spina bifida.
- Urological assessment is an integral part of ongoing management of spina bifida at all ages.
- Progressive loss of mobility profoundly decreases the quality of life for people with spina bifida. Attending to orthopaedic issues and encouraging appropriate physical activity helps to minimise the impact of progressive loss of mobility.
- Incontinence management is not just an aesthetic issue — it is a key barrier to achieving independence for young people and adults with spina bifida.
- Dealing with sexuality and reproductive issues is a routine part of managing spina bifida.
- Paediatric centres can help GPs locate adult spina bifida treatment centres. In the absence of adult centres, paediatric centres routinely offer support for adults with spina bifida.
- Cognitive dysfunction often adversely affects perception of symptoms and the ability of the patient to follow medical management instructions.