

Important Information for Patients With Spina Bifida (Bladder cancer)

Research has found that patients with spina bifida are increasingly being found to develop bladder cancer.

They often present late in the disease process, and have a poor prognosis. Many of the symptoms are vague, or symptoms which adults with spina bifida may experience throughout their lives (haematuria, recurrent UTI, incontinence). In addition, cognitive issues might lead to a further delay in seeking medical advice.

A recent systematic review of bladder cancer outcomes in patients with spina bifida* found:

- Bladder cancer risk of around 4%, both with or without augmentation
- Patients often present with at a late stage (III or IV)
- Mean age of 41 years
- Survival Rates are poor, at around 32% after two years
- Risk is recognised for augmented bladders but less so for non-augmented
- Around 10% of cases were asymptomatic, and identified through routine surveillance (Many adult patients have no routine urological surveillance)

Please discuss the risk of bladder cancer with your patients with spina bifida and remind patients to report new developments of:

- frank haematuria,
- recurrent UTIs,
- abdominal/pelvic pain,
- difficulty with Clean Intermittent Catheterisation (CIC)
- bowel obstruction

With the significant risk of bladder cancer and late diagnosis in mind please consider a low threshold for urological investigation.

*Systematic Review of bladder cancer outcomes in patients with spina bifida, K.O Rove, D.A Husman, D.T.Wilcox, G.J. Vricella, T.T.Higuchi, Journal of Paediatric Urology (2017)