

Position Statements

The following statements reflect the charity's position on the following issues that relate directly to our vision and aims in the following:

- Prevention of Neural Tube Defects
- Fortification of Flour with Folic Acid
- Folic Acid supplementation prior to and during pregnancy
- Prenatal surgery for spina bifida
- Termination of pregnancy
- Specialised Commissioning

Prevention of Neural Tube Defects (NTDs)

SHINE values and celebrates the lives of all its members, and fully appreciates the role of spina bifida in the identity and life history of our members with it. It may appear that our work on primary prevention of spina bifida is at odds with this. **SHINE** raises awareness of the role of folic acid and B12 in preventing NTD, and this enables people to choose to reduce the chances of their future children having a NTD, or to choose not to, according to their values and beliefs. Nearly 50% of NTDs are fatal, before or shortly after birth. Anencephaly is always fatal, causing great distress for hundreds of parents-to-be every year.

Fortification of flour with folic acid.

SHINE believes that fortification of flour, to be used for white bread and other baked products, would lead to a reduction in the number of neural tube defects in the UK, as it has in the 81 countries across the world that have done this or similar. Recent blood analyses of folate in the general population show levels of folate insufficiency at around 70%, of teenagers and women of all ages, and that fortification would help improve this public health problem. Folate deficiency is associated with many health problems in addition to increased chance of pregnancy affected by NTD

The aim of fortification is to add small doses of folic acid to the diet over time, which will help protect the 70% of women who don't take any folic acid, or don't start until they're pregnant, from having their pregnancy affected by spina bifida or anencephaly.

SHINE is leading a campaign, calling upon the Government to introduce mandatory fortification of flour with folic acid. A Government consultation on the issue will be issued early in 2019.

Folic Acid supplementation prior to and during pregnancy

Women preparing for pregnancy, and wishing to reduce the chance of their pregnancy being affected by NTD should take a supplement of 400mcg of folic acid for 2-3 months before they stop contraception. If fortification goes ahead, women should still take a supplement, and will be safe to do so.

Prenatal surgery for spina bifida

Prenatal surgery for spina bifida is now available in the UK. The outcomes are variable and unpredictable, with significant risks to both the fetus and the mother. Long term outcomes on the benefits, compared with traditional post-natal surgery, have not yet been ascertained. **SHINE** will direct parents-to-be to discuss their options with their Fetal Medicine Team at the earliest opportunity, if they express an interest in this surgery. **SHINE** will play no role in the decision to proceed but will offer support during this period.

Termination of pregnancy

In England and Wales, termination of a pregnancy affected by a disabling condition is a legal right given to parents-to-be in these circumstances. As it is legal, **SHINE** supports a family's right to choose termination if this is right for them, but believes that accurate information, based specifically on their test findings, and given by a specialist knowledgeable in the diagnosed conditions, is the only basis upon which parents-to-be can make that decision. **SHINE** supports parents-to-be in a non-judgemental way, to make that decision by providing information, and identifying appropriate specialists.

Specialised Commissioning

SHINE is concerned by the fragmented nature of health services for adults with spina bifida, and by the current model of care that requires people to become ill before referral can be made. Spina bifida is uncommon and complex, and expertise is scant. In addition, adults with spina bifida may need monitoring of their health, support to engage effectively with health services, and support to manage their conditions, because of cognitive impact of their condition.

In order to address this need, **SHINE** is working to have spina bifida recognised as a condition deserving Nationally Commissioned Services, which would lead to a defined and equally-accessible service across England.

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