



Approach to pregnancies with history of fetal anomaly in previous pregnancy or after diagnosis of fetal abnormalities.

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- Recurrence risks for familial congenital anomalies in successive pregnancies are known, but this information for major structural anomalies is lacking. The absolute and relative risks of recurrent congenital anomaly in the second pregnancy for women with a history of a congenital anomaly in the first pregnancy, for all major anomaly groups and subtypes have been estimated in different studies.
- Absolute recurrence risks varied between 1 in 20 and 1 in 30 for most major anomaly groups. At pre-conception and antenatal counselling, women whose first pregnancy was affected by a congenital anomaly and who are planning a further pregnancy may find it reassuring that, despite high relative risks, the absolute recurrence risk is relatively low.



- Although approximately 50% of all congenital anomalies cannot be linked to a specific cause, there are some known genetic, environmental and other causes or risk factors.
- Some congenital anomalies can be prevented. Vaccination, adequate intake of folic acid or iodine through fortification of staple foods or supplementation, and adequate antenatal care are examples of prevention methods.



Decision-making after ultrasound diagnosis of fetal abnormality

- there are several options for the obstetric management, ranging from standard care to non-aggressive care and termination of pregnancy.
- An important question is to what extent the couple should be supported in decision making when a fetal abnormality is diagnosed.
- Parents may attend counselling sessions to assist in gathering information about their baby's condition, adjusting to the diagnosis, and making decisions about their baby's care



- Studies showed that parents prefer to receive comprehensive information about their baby's condition from a knowledgeable health professional as soon as she possible after prenatal diagnosis, supplemented by written, visual and web-based resource



Continuing pregnancy after diagnosis of T13-18

- Based on the information obtained in a study from parents who continued their pregnancy after a diagnosis of T13-18, they offer suggestions to assist healthcare providers to provide optimal pre-natal care.
 1. At the time of diagnosis, provide accurate survival figures. Avoid words like “lethal,” “incompatible with life” and “vegetable”. Avoid value-laden language related to disability.
 2. Parents should be informed that most parents who chose to continue pregnancy have reported a positive and enriching experience regardless of the lifespan of their child.



- 3. Parents who decide to continue their pregnancy need support, not judgement or pressure to change their choice. Parents accept that early death is likely and they have chosen to value the time they have, both before and after birth.
- 4. Remember that to these parents, their child is a person, not a diagnosis. Refer to the unborn child by name, if possible. Parents expect to receive medical information related to their child, not to the diagnosis. Informing parents of normal organs in addition to anomalies is greatly appreciated.

Offer hope when it is reasonable: hope that baby will continue to grow in utero, hope that baby will be born alive and that parents will enjoy some time with baby.



- 5. Offer to continue prenatal and fetal care as for any pregnancy. Ultrasounds are very special, memorable events and given the high risk of miscarriage, might be the only time parents will see their living baby. Taking a few minutes during the ultrasound to point out normal or “cute” features of the baby can be a lifetime gift to parents.
- 6. Guide parents to create a birth plan that is best for their child and family. Parents should understand that children with T13 or 18 are unique and some might benefit from life sustaining interventions while some may be harmed by them.
Ensure that the birth plan includes collectables for memories such as foot prints and photographs. If indicated, be transparent with parents about any hospital protocol or policy that restricts certain interventions to babies born with T13-18. Parental challenges to these restrictions should be discussed in a multi-disciplinary meeting or ethics consultation

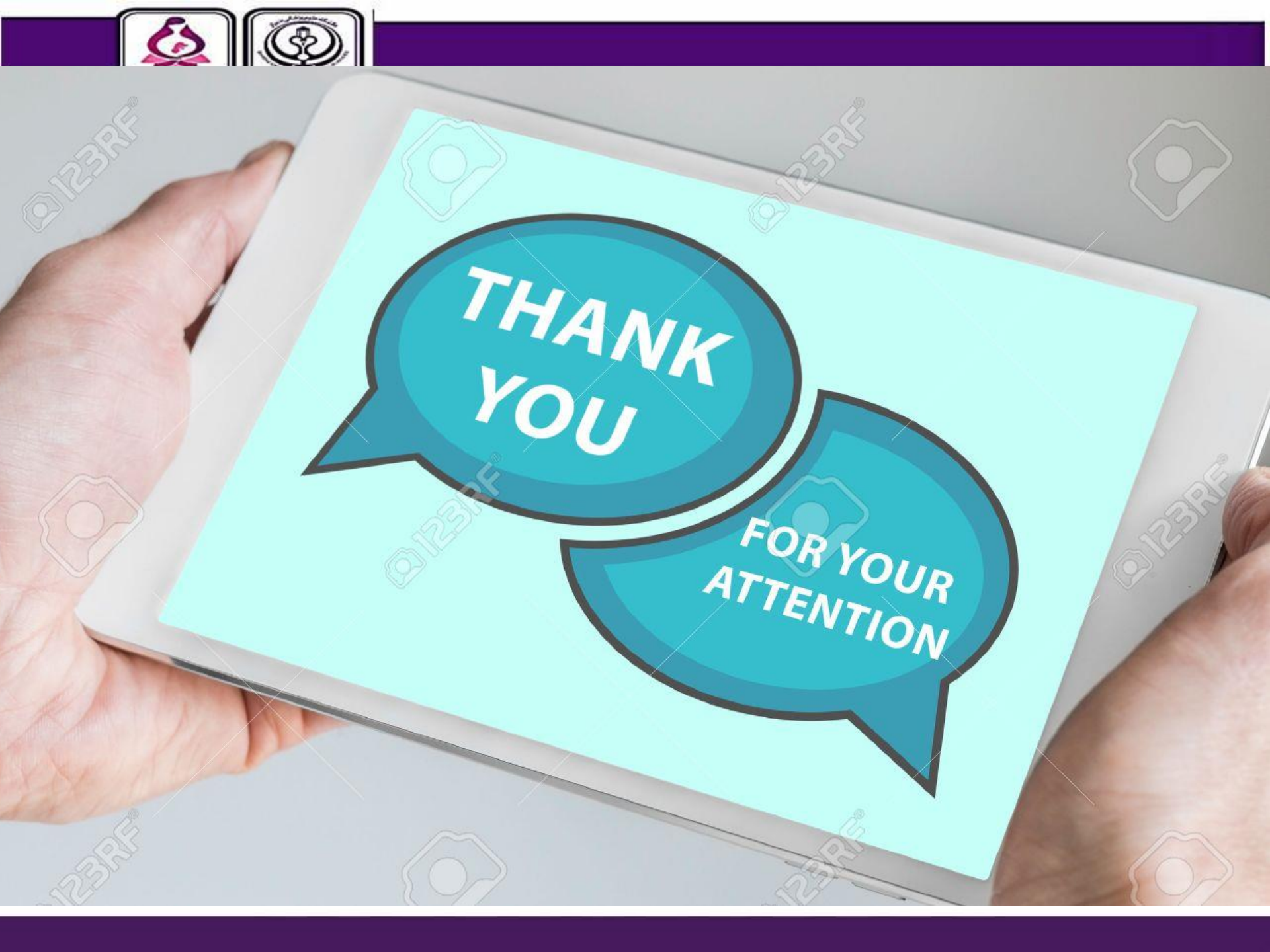


- 7. Most parents who choose to continue pregnancy do so because it is the better path according to their personal beliefs. They appreciate empathy and kindness on their extraordinarily difficult journey, especially recognition of and respect for their love for their child.



Conclusion

- the diagnosis of a severe congenital anomaly and the subsequent pathway that parents face is a traumatic event.
- Responsibility for the decision to terminate the pregnancy intensifies emotions and adds to the complexity of caring for this group.
- These findings point to the need for a specific care pathway for parents undergoing this difficult experience.
- Recommendations include the need for a greater understanding of the views of who caring for these parents, review of specific training needs, and examination of processes to better support both parents.



**THANK
YOU**

**FOR YOUR
ATTENTION**