

# CDH Patient Journey

## Pregnancy

### What happens?

- Counselling
- Genetic testing
- Further scans
- Complications
- Fetal Therapy (FETO) if suitable
- Termination of Pregnancy if opted

### Challenges

- Decision making
- Birth plan
- Care plan
- Mental health
- Inclusivity
- Complications
- Bereavement

## Birth

### Challenges

- Options
- Labour
- Bonding
- Mental health
- Recovery
- Bereavement

### What happens?

- Induction or spontaneous labour
- Baby treated post-birth
- Baby transferred to on-site NICU or another specialist unit
- Still birth

Focus should be on the patient as a whole and not just the hernia or condition at birth.

Patients should not only survive, but thrive.

## Hospital

### Challenges

- Postnatal care
- Bereavement
- Mental health
- Family & friends
- Environment
- Work/school
- Self-care
- Feeding
- Bonding
- Finances

### What happens?

- Birth mother discharged
- Baby in NICU/PICU
- Weaning off ventilator/oxygen/medications
- Feeding established
- Baby discharged to local hospital or home
- Data captured

### What helps throughout the journey?

- Follow up
- Options & choices
- Good information & communication
- Patient involvement & centredness
- Decision making tools and support
- Signposting to external support
- Good counselling & psychological support
- Liaison between medics and care settings
- Transition planning
- Feeding support

### Who can help?

- Fetal medicine specialists
- Obstetricians & midwives
- Paediatric consultants
- Geneticists & genetic counsellors
- Neonatologists & neonatal nurses
- Speech & language therapists
- Patient organisations/charities
- Paediatric nursing staff
- Dieticians & nutritionists
- Family & friends
- Psychologists
- Social workers
- Chaplains

### What happens?

- Outreach nurses
- Postnatal care
- Follow up appointments
- Loss of confidence
- Symptoms

## Childhood/Adulthood

### What happens?

- Ongoing issues varied in type and severity
- Symptoms
- Reherniation
- Childhood ailments
- Transition from child to adult services
- Hospital appointments/admission

### Challenges

- Transition of care
- General/mental health
- Feeding & nutrition
- Exercise & social activities
- Body image
- Awareness
- Isolation
- School/work
- Relationships
- Pregnancy & birth
- Research

### Endocrine system

- Growth
- Hormonal

### Skeletal

- Chest wall deformities
- Foot problems
- Scoliosis

### Development

- Neurological
- Development delays
- Mental health
- Growth

### Cardio and respiratory

- Oxygen supplementation
- Recurrent chest infections
- Pulmonary hypertension
- COPD and asthma
- Rapid breathing
- Tracheomalacia/bronchomalacia

### Muscles

- Compromised diaphragm
- Poor muscle tone (hypotonia)

### Gastrointestinal

- Motility/blockage/gastroparesis
- Adhesions
- Malrotation
- Reflux

### Sensory

- Speech and language
- General sensory issues
- Sight issues
- Hearing loss
- Oral aversion

### Feeding and nutrition

- Lack of calorie intake
- Physical problems (chewing/ swallowing)
- Sensory issues (textures)
- General feeding difficulties
- Failure to thrive
- Picky eating
- Oral aversion

What will help achieve a good future for my child?

Transition of care is so important

## Home

### Challenges

- Ongoing medical needs
- Awareness/lack of knowledge
- Isolation
- Mental health
- Finances
- Family dynamics
- Loss of confidence
- Data capture/research

## Bereavement

### What happens?

- Unexpected death during pregnancy or after birth
- Termination of pregnancy
- Stillbirth
- Grieving process
- Post-mortem offered

### Challenges

- Lack of services
- Follow up
- Mental health
- Delayed grief
- Isolation
- Relationships
- Family & friends
- Family planning
- Post-mortem
- Data capture/research

### What can help?

- Research
- Midwife support
- Partner involvement/support
- Information and signposting
- GP and health visitor liaison and monitoring
- Choices e.g baby at home
- Memorial creation
- Reflection of care

## way out

The key is to put patients at the centre of their care

The aim is to provide the patient with a Good Quality of Life