Endocrine Transition Framework

Developed by the SPEG Transition Group
Approved by the SPEG Steering Group
Version: 1
Current Issue Date: August 2018
To be reviewed: August 2021

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SECTION 1: Introduction

The transition from childhood to adulthood is an important stage in a young person's life. For adolescents with particular health care needs, this is a time when they can be expected to take increasing responsibility for their own health. Adolescents with long-term conditions are less likely to adhere to medical advice than younger children [1]. This can affect health outcomes in adulthood [2]. Adolescents with endocrine conditions can lose contact with healthcare services during the transition period [3] and this disengagement with services can have adverse effects on health [4, 5]. There is therefore consensus that the needs of adolescents and young people need to be actively managed during this transition period [6-8].

SECTION 2: Definition and Aims

Definition of transition

Transition is a "planned, purposeful movement of the young person from a child centred to an adult orientated health care system". It is a process which evolves over a considerable period of time and should not be considered an event [9].

Transitional care is a multi-dimensional, multi-disciplinary process that addresses not only the medical needs of young people as they move from children's services to adult services, but also their psychosocial, educational and vocational needs and the needs of their parents.

The aims of transitional care are to:

- Provide high quality, co-ordinated, uninterrupted health-care, that is patient-centred, age and developmentally appropriate and culturally competent.
- Be flexible, responsive and comprehensive with respect to all persons involved.
- Promote skills in communication, decision-making, assertiveness and self-care, self-determination and self-advocacy.
- Enhance the young person's sense of control and move towards independence.
- Provide support for the parent(s)/guardian(s) of the young person during this process.
- Provide care in a young-person friendly environment

SECTION 3: Key elements for an effective transition programme

1. A written policy
2. The opportunity to meet the adult physician in advance of the planned movement into the adult service.
3. A preparation period and education programme with an individualised approach, which addresses psychosocial and educational/vocational needs, provides opportunities for adolescents to express opinions and make informed decisions, and gives them the option of being seen by professionals with or without their parents depending on their wishes.
4. A co-ordinated transfer process with a named co-ordinator and continuity in health personnel when possible.
5. Administrative support.
6. Primary health care and social care involvement.
7. Young person friendly clinic facilities.

SECTION 4: Philosophy of Transition

- A transition programme is an essential part of quality care for adolescents with endocrine conditions.
- Effective transition must recognise that transition in health care is only one part of the wider transition from dependent child to independent adult.
- Transition services must also address the needs of the parent/guardian(s) whose role is evolving at this time in their son/daughter's life and health-care.
- In moving from child-centred to adult health services, adolescents undergo a change that is cultural as well as clinical.
- Transition services must be multidisciplinary and involve both paediatric and adult teams, and any other parties involved in the care of the adolescent.
- Co-ordination of transitional care is critical, and a key worker should be identified for each adolescent to ensure seamless transition.
- Transition is NOT synonymous with transfer. Transition is an active *process* and not a single event like transfer. Transition must begin early, be planned and regularly reviewed, and be age and developmentally appropriate.
- Transition services must undergo continued evaluation.

SECTION 5: Preparation for Transition

Principles

- Both the teenager/adolescent and their parent(s) need to be prepared for transition and eventual transfer to the young adult service.
- There must be a flexible approach to transition which takes into account developmental readiness and links to other social transitions such as leaving school.
- Adolescents should only be transferred to the young adult service when they have completed growth and puberty and have the necessary skills to function in a young adult service largely

independent of parents and staff e.g. decision-making, communication, self-care, assertiveness. When this is not possible due to cognitive impairment and/or severe disability, appropriate advocacy, preparation and developmentally appropriate care in the adult service should be ensured prior to transfer.

- Transition planning must begin well before the anticipated transfer time – preferably in early adolescence when a series of educational interventions should discuss understandings of disease, the rationale of therapy, source of symptoms, recognising deterioration and taking appropriate action, and most importantly, how to seek help from health professionals and how to operate within the medical system, including primary and emergency care.
- Adolescents should be helped to take appropriate responsibility for their health from as early an age as possible. Furthermore, their parents should be encouraged to help them to do so. Health promotion should be embedded into the young person's service.
- The concept of independent visits must be introduced well in advance to prepare the adolescent and their parents for this. "In the next couple of years you may feel able to start seeing the doctor on your own…." The aim should be to see the teenager/adolescent by themselves for some time during clinic visits. NB Parents must remain involved and should be seen with the adolescent at some time during the session if this is desired by the young person.
- In preparation for adolescents to be seen independently, the teenage and young adult clinic will provide continuity of professionals at each visit.
- A schedule of likely timings and events should be given in early adolescence and they should be involved in developing detailed timings for their own transition. Details should be documented in the notes to ensure continuity especially if seen by different members of the multi-disciplinary team.
- Leaflets and material about transition should be provided in clinic settings from early adolescence.

SECTION 6: Timings and age

Timing of transition MUST be flexible and not restricted to age criteria only. There must be a flexible approach to transition, the timing of which depends on

- chronological age,
- maturity,
- adherence,
- independence,
- adolescent readiness,
- parental readiness.
- Links to other social transitions such as leaving school

SECTION 7: Process of transition

Preparation for Transition

Initiation & co-ordination of transition

Every consultant or nurse seeing children and young people in the clinic is responsible for ensuring discussion of transition and making arrangements by a designated team member. This should be documented in the clinical notes. Post-clinic meetings or MDTs offer potential opportunites to identify adolescents suitable to begin transition at the next appointment.

Educational programme

- Introductory leaflet which includes the meaning of transition for the patient and parent at the initial discussion.
- Gradual increasing emphasis on increasing self advocacy for the adolescent in clinic. This includes involvement in decision making, being seen alone and other issues which impact on their life.
- If a competency checklist is used by the paediatric department, this should transfer with the young person as they move into the adult service.

Assessment of readiness for transition

This will involve individual discussion between the adolescent and their parents with the endocrine team and team discussion at post clinic meetings. The ultimate decision to move to the adult service lies with the young person.

Involvement of GP in transition process

The GP needs to be sent a copy of the transition plan.

Acknowledgements:

This policy has been based on the work done by the Paediatric subgroup of the Scottish Diabetes Group, which in turn has based their transition policy on the work of the North-West Paediatric Network. SPEG acknowledges their work and is grateful that they have made this policy available.

SECTION 8: References

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Section 9: National Standards for Endocrine Transition

Principles

- Age appropriate communication – with the young person as well as the parent/carer.
- Offer the young person the option to see the HCP without parent/carer for at least part of the consultation.
- Understand health issues in the context of other events in the young person's life.
- The appointment should aim to develop mutually-agreed goals, working towards an appropriate level of independent self-management by the young person.
- Aim for consistency of contact – not necessarily through one person but a small team
- A balance of paediatric and adult healthcare professionals to see the young person.
- Team members should be working collaboratively across both services with a shared ethos and an understanding of each other's roles and responsibilities.
- All professionals need to be appropriately trained and specifically interested in the needs of young adults living with a long term condition.
- The process should allow the young person to become familiar with the location, layout and staff involved with the young adult service.

Process

- An identified lead for transition in each paediatric and adult endocrine service.
- A joint paediatric/adult transition policy.
- Start the discussions about the transition process early.
- The actual period of movement between services should involve input from paediatric and adult teams with at least one combined appointment.
- Experience of care audit should be undertaken.

Quality Standards for Transition

- Ensure there is a patient centred transition policy in place for every unit.
- The young person and their family should be given information relevant to them about the transition process in advance of the process starting.
- The young person, family and carers should be involved in planning their transition process.
- Identify a named member of staff the family can contact regarding the transition process.
- The move from paediatric to adult care should involve at least one combined appointment.
- DNA rates monitored and followed up over the course of the transition period.
- Children with GHD should have GH status retested at final height and a decision made about ongoing GH replacement as part of the transition process.
- There should be a regular experience of care audit for each transition service.

SECTION 10: Information matrix

TRANSITION CHECKLIST – MATRIX FOR INFORMATION

Q1	Have the patient & their family / carers been informed of the transition process well in advance of the process beginning?	**STOP** The issue of transition has never been raised with the young person or their family / carers. Any questions raised have not been answered.	**CAUTION** The issue of transition has been briefly mentioned to the young person and their family / carer. Questions raised have been partially answered.	**GO** The issue of transition has been discussed fully and openly and any questions raised have been answered as comprehensively as possible.
Q2	Does the information given begin by explaining what transition will cover and then continue to cover that information?	**STOP** Does not give an introduction or any outline of the information, and the information is not very clear.	**CAUTION** Has an introduction but does not contain any relevant information that isneeded for the patient/family or carer.	**GO** Information is in a clear, concise manner and contains information mentioned in the introduction.
Q3	Does it use everyday language (plain English) explaining unusual or medical words or abbreviations or jargon?	**STOP** Does not contain any plain English (everyday language) and has many medical terms, it does not make any attempt to explain the medical terminology.	**CAUTION** Has a mixture of plain English (everyday language) and medical terminology, and makes some attempt to explain medical words but not in great detail.	**GO** Information is in plain English (everyday language) and no medical jargon; any medical terminology should give a clear explanation of its meaning.

Q4	Does any written information use short sentences of less than 15 words on average?	**STOP** The information contained in the sentence has too many words with no clear explanation. Edit into one short sentence.	**CAUTION** The information is written in sentences containing more than 15-20 words and is explaining about more than one concept in the sentence, this can be confusing. It would be better split into two sentences.	**GO** The information contains sentences of less than 15-20 words and only one concept at a time. It's important to use short sentences, and not too many conceps.

TRANSITION CHECKLIST – MATRIX FOR INDIVIDUAL & INTERACTION

Q5	Is there a clear written policy in place for the transition pathway for this particular service?	**STOP** There is no policy in place at all for transition from children's services to adult services	**CAUTION** There is a partial process in place for the transition pathway but this is not a written policy	**GO** There is a written policy in place for the transition from children's services to adult services.
Q6	Has a predicted timescale of transition been provided to the young person?	**STOP** There has not been a predicted timescale of transition given to the young person	**CAUTION** A predicted timescale of transition has been provided for the young person but this has not been discussed fully	**GO** A predicted timescale has been provided for the young person and has been fully explained to them, including the issue that this is not a

				definitive timescale and may be subject to change for reasons that have been fully discussed.
Q7	Has the individual needs of the patient been taken into account – age, development, maturity etc?	**STOP** The individual young person's needs have not been considered	**CAUTION** The individual needs of the young person have been considered but not fully and there is still more to consider	**GO** The individual needs of the young person have been considered and fully incorporated in to the transition process for this patient
Q8	Has the young person been prepared for gaining more independence in the move to adult services and feels confident about this autonomy?	**STOP** The young person has not been prepared for the independence expected in adult services and no help has been given to improve this. The subject of attending clinics on their own has not been broached.	**CAUTION** The young person has begun to partially understand the independence expected of them but is not yet fully confident in being autonomous in the adult services. The subject of attending clinics on their own has been discussed but not in detail.	**GO** The young person fully understands the independence expected and are comfortable and confident in being autonomous and attending clinics on their own in the adult services. They have been given all the detail required for them personally.

TRANSITION MATRIX – SERVICE & INTERACTION

Q9	Is there the opportunity to have joint clinics with both children's service staff and adult service staff?	**STOP** The opportunity for joint clinics has not been considered	**CAUTION** There is an opportunity for joint clinics but this has not been developed further	**GO** The opportunity for joint clinics has been fully considered and has been arranged where possible
Q10	Are the children's team and adult's team working collaboratively to ensure a smooth transition process?	**STOP** The children's team and adult's team have not discussed the transition pathway at all	**CAUTION** The children's team and adult's team have partially discussed the transition pathway but not in full detail	**GO** The children's team and adult's team have discussed the transition pathway and are fully aware of the patient and the pathway that will be put into practice
Q11	Does the information / staff member personally address the patient / family or carer?	**STOP** Does not address the patient / family or carer as "you" or "your" and uses a lot of passive sentences.	**CAUTION** Addresses the patient / family or carer as "you" or "your" but uses passive sentences, explains details but uses words that are impersonal to the participant / patient / family.	**GO** The information addresses the patient / family or carer as "you" "your" and tries to address any fears and anxieties. It gives reassurances to the patient / family. It also uses personal

				terminology.
Q12	Is the tone of Interaction / information respectful?	**STOP** The information / Interaction talks down to the patient / family and does not provide any encouragement for the patient / family or carer. Is rather patronising to the patient / family or carer.	**CAUTION** The information / Interaction uses words that are patronising and does not try to encourage involvement. Try and rethink the information / interaction in a more realistic form.	**GO** The information should encourage involvement with the patient/family and is not patronising in any way. Do not talk down to the patient / family or carer. It should not stereotype or discriminate to any group