

SICKLE CELL DISEASE & THALASSAEMIA – TRANSITION PLANNING CHECKLISTS

These checklists are designed to stimulate thought and discussion around transition issues for children and adolescents with Sickle Cell Disease or Thalassaemia.

Early Stage (12-14 years)

Self-advocacy

- Educate the child in describing their sickle cell disease or thalassaemia, including medication taken, how to get help and the signs of deterioration. Review with family
- Encourage the child to ask questions during each appointment

Autonomy

- Discuss the medications and treatments needed daily, including problems or barriers to compliance
- Discuss purpose of emergency treatments, if relevant, and advise how to seek help from others if parents are not present
- Discuss transition and why it is undertaken

Psychosocial

- Talk to the child about social activities, peer involvement and supportive relationships
- Discuss external support options with the young person (peer support, internet, support groups, Sickle Cell Society, UK Thalassaemia Society)

Educational

- Talk about responsibilities at home (e.g. chores)
- Discuss restrictions on educational or recreational activities
- Discuss strengths at school for later subject choices

Health & Lifestyle

- Ask about smoking and use of alcohol
- Discuss the impact of above behaviours on health and general well-being

Sexual Health

- Discuss pubertal changes, differences from peers and the impact of puberty on their condition
- Discuss where the child and parents can obtain information about sexual health

Parents & Family

- Provide parents with the opportunity to discuss their feelings about loss of control, concerns about the future
- Discuss how parents may help to facilitate their adolescent's independence. Encourage parents to prepare and support their adolescent to start asking direct questions of the health care team

Signed.....Date.....

Middle Stage (14-15 years)

Self-advocacy

- Discuss strategies to access support and information about their condition and treatments (e.g. peer support, internet, support groups, voluntary sector)
- Direct questions to the adolescent, with the expectation they will answer them
- Provide and encourage the opportunity to discuss concerns and questions (especially about topics such as sexual health) with the adolescent alone

Autonomy

- Check that the adolescent understands the differences they may experience between the paediatric and adult services
- Encourage them to learn about their medication and prescriptions
- Discuss when, and how to seek emergency medical help
- Discuss increasing independence at home (taking own medication, remembering appointments)
- Encourage the adolescent to make the next appointment, call to change an appointment talk to the receptionist, and discuss transportation (if required)

Psychosocial

- Prompt the adolescent and parents to express positive goals for self and health
- Identify support systems outside the family, encourage leisure activities such as joining a club at school, a peer support group or voluntary group

Educational

- Focus discussion on school; strengths, plans for future study, employment, or vocation
- Encourage visits to school career advisors to talk about career preparation, work experience or volunteering

Health & Lifestyle

- Discuss issues of body image feelings, communication with peers and concerns regarding dieting, exercise, weight gain or loss, smoking, alcohol and risk taking behaviour

Sexual Health

- Make comments or raise topics around sexuality, growth and development due to puberty. Do not expect or require a response
- Encourage the adolescent to ask questions to clarify the impact of their condition and/or medications on sexuality

Parents & Family

- Allow time for parents to express their own issues or concerns about transition without the adolescent present
- Explore ways parents can help educate and support young person to further increase their independence

Signed.....Date.....

Late Stage (15-16 years)

Assess to ensure readiness to transfer to adult services

Self-advocacy

- Discuss with the adolescent how they are going to be introduced to the adult services
- Discuss their concerns about the transfer to adult services

Autonomy

- The adolescent knows who to contact for future health needs (names and telephone numbers).
- The adolescent has met with adult team, and made a visit to the adult wards and day-care unit before discontinuing paediatric care

Psychosocial

- Have the adolescent identify people he/she can contact for help or advice including social and psychological support

Health and lifestyle

- Identify any needs for personal assistance in care or issues of living away from family
- Discuss smoking, use of alcohol and drugs, the interaction with medication and impact on their condition
- Discuss any risk-taking behaviour.

Sexual Health

- Discuss sexual maturation, fertility, and vulnerability

Educational & Employment

- Discuss employment or vocational options
- If choosing college or university, discuss living arrangements, impact on health condition, and access to appropriate medical treatment and support away from home

Parents & Family

- Discuss with parents their changing role as support person rather than main carer to adolescent
- Encourage parents to feedback issues around the transition process

Signed.....Date.....