West of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network

WoSPGHaN NHS SCOTLAND

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Guideline

Transition of young people with chronic gastroenterological diseases from paediatric to adult services

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Responsible Director	
Approved by WoSPGHaN	
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”there is a requirement to ensure that transition to adult service … is recognised in its own rights by health professionals, service providers and young people themselves as a vital element of the patient journey”

Royal College of Physicians of Edinburgh (2008)[1]

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In line with the commitment of the NHS to remove discrimination and promote equality, this policy and guidance recognises and accounts for the specific inequalities experienced by people because of age, disability, sex, gender, reassignment, race, sexual orientation, religion, belief system, pregnancy and/or maternity. In addition it recognises and accounts for the broader range of social inequalities that can impact on health outcomes such as poverty, literacy or geography [2].

1. Introduction

Definition
The term Transition describes a process whereby the care of a young person is transferred from a paediatric team to an adult team. The National Service Framework for Children, Young People and Maternity Services (2004) provides a useful definition of transition describing "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults as they move from child-centred to adult-oriented health care systems" [3]. This process includes, but is not limited to, the formal handover of care from one team to the other.

Goal
The goal of transition is to provide health care that is "uninterrupted, co-ordinated, developmentally appropriate and psychologically sound prior to and throughout the transfer into the adult system" (Paone et al 2006)[4,5,6].

Rationale
It has been widely acknowledged that there is a difference in culture between children's hospital services and adult hospital services[7]. A children's hospital hosts the majority of medical specialities, whilst in adult services medical specialists can be spread across a number of hospitals, making continuity of care more complex and attendance more challenging for families moving from the centralised children's hospital.

This can result in a complex transition process which often arises at a challenging time for young people, as they are already experiencing a multitude of personal, educational, social and health changes (e.g. leaving school, starting to work or further education). Hence, it is the task of services to ensure that the transition process is both efficient and effective in order to reduce further distress caused by such change[8, 9].

Delivering a Healthy Future - An Action Framework for Children and Young People's Health in Scotland (2007) establishes clear standards for promoting the health and wellbeing of children and young people and for providing services, which meet their needs. The section "Reflecting Patient Focus – Age Appropriate Services and Advocacy" includes the recommendation that transition "…from children's to adult services, which inevitably takes place during the care of young people with long-term conditions, is undertaken in a structured, consistent and well-understood manner which is fully centred on the patient's needs. For young people with complex needs the transition needs to be effectively managed in partnership with education and social work services, with a clear focus on delivering the desired outcomes for the young person" [10].

This guideline is being introduced to ensure that the transition of care for all young people with chronic Gastroenterological, Hepatological and Nutritional (GHN) diseases from paediatric to adult services is carried out consistently, taking into account each individuals medical, developmental, psychosocial and educational/vocational needs and ensuring as little disruption to care as possible [11].

Plan
In order to facilitate smooth transition and appropriate joint working arrangements, it is suggested that a regular interface be established between paediatric and adult gastroenterology services, ideally in the form of a jointly-held Transition Clinic[12, 13]. Further, all professionals need to be aware that this may not be the only transition

happening for each young person at this time and so they will need to involve the young person and their family in this process and discuss with them where their care will be ultimately transferred [6].

2. Principles

i) The needs of the young person and not of the service come first and foremost.

ii) The Equality Act (2010) requires each patient to be treated as an individual so that their unique needs can be identified and met within health care. Account needs to be taken of age, disability, gender, sexual orientation, spiritual belief and culture, along with social inequalities.

iii) As a general principle, the transfer of care should be carried out when the young person is physically and emotionally mature enough to accept the roles and responsibilities involved in attending an adult PGHN clinic.

iv) Transfer of care should not be undertaken when the young person is acutely unwell.

v) Transition describes a process, not a single event. The process should start a minimum of 18 months prior to leaving paediatric care [13].

vi) Transition needs to involve the young person in decisions and the plans. It is therefore important to ask their views.

vii) It is essential that language used is understood by the young person in all planning, consultations and discussions[14].

viii) Each young person should receive a care plan detailing the process at the outset. This care plan should detail the pathway of care and the responsibilities expected of the young person in the process[15].

ix) All agencies relevant to the transition process will be copied into correspondence when the young person enters the process.

x) Any correspondence to the family during transition will be sent to young person and copied to their parents/guardians.

xi) Staff should involve the parents/guardians in the preparation for transition and educate the whole family about the new model of care the young person will encounter within adult services[14].

xii) Young people should attend a minimum of one (optimally two) joint appointments held between paediatric and adult GHN teams if available. If not available, see Section 7 for transfer.

xiii) There must be clear lines of responsibility for provision of care for the young person (including emergency care in the event of an acute exacerbation/deterioration) at every stage in the transition process.

xiv) A detailed and comprehensive multidisciplinary case summary must be provided for every young person on exit of the transition process where appropriate.

xv) Database support is required to support the transition process.

3. Scope

The WoSPGHaN transition guideline aims to promote the smooth transition where appropriate for young people aged 14-18 from paediatric services to adult services. It is aimed at all professionals across a wide range of disciplines involved in the care of young people with chronic GHN diseases.

Services for children and adolescents with GHN conditions in the West of Scotland are as follows:

- Paediatric Gastroenterology Department, Royal Hospital for Children, Queen Elizabeth University Hospitals, Govan Road, Glasgow.
- District General Hospital Paediatrics (including Paediatricians with Special Interest):
  - Crosshouse Hospital
  - Dumfries and Galloway Royal Infirmary
  - Royal Alexandria Hospital, Paisley
  - Wishaw General Hospital
  - Forth Valley Royal Infirmary
  - Inverclyde Royal Hospital

Services for adults with GHN conditions in the West of Scotland include adult GI services in:

- Glasgow (Glasgow Royal Infirmary, Queen Elizabeth University Hospital, Victoria Infirmary, Gartnavel General Hospital)
- Royal Alexandra Hospital, Paisley
- Vale of Leven District General Hospital
- Inverclyde Royal Hospital
- Crosshouse Hospital
- Ayr Hospital
- Wishaw General Hospital
- Hairmyres Hospital
- Monklands Hospital
- Dumfries and Galloway Royal Infirmary
- Stirling Royal Infirmary
- Forth Valley Royal Hospital

Primary Healthcare professionals involved in the care of young people with GHN disease, including:

- General practitioner
- Community children's nurse
- District nurse
- Health visitor

Supporting services include:

- Paediatric surgery
- Adult surgery
- Other paediatric subspecialties

- Allied health professionals, including dietetics, speech and language therapy, gastrostomy and stoma nurses, physiotherapy, occupational therapy and social work
- Radiology (in each centre)
- Pathology
- Paediatric Supra-regional Liver and Intestinal Failure Units
- Supra-regional Adult Liver Transplant Unit
- Charitable patient and family organisations (including NACC, CICRA, CLDF).
- Paediatric Psychology Service or Child and Adolescent Mental Health Services
- BUPA Healthcare
- Homeward Healthcare

The WoSPGHaN transition guideline is pertinent to all young people identified as having chronic disease affecting the gastrointestinal tract or liver and young people with chronic nutritional problems.

It is also recognised that, although the transition process describes a process of moving a young person from paediatric to adult care, some adolescents with gastrointestinal disease (in particular Inflammatory Bowel Disease) may be diagnosed/identified by adult GI/surgical teams. It is encouraged that these young people are referred back into paediatric care and entered into the transition process at the appropriate time[16].

4. Roles and Responsibilities

All staff working with young people with chronic GHN conditions within West of Scotland are expected to work within this framework to facilitate the effective transition of young people from paediatric to adult care. This includes staff across a wide range of disciplines working in primary, secondary and tertiary care, with support from management and administrative staff.

4.1 Administration

a) Data manager

i. Identification of potentially eligible young people for entry into the transition process.
ii. Ongoing documentation of stage of transition as young person progresses through the process.
iii. Identification of patients for inclusion into joint transition clinics where appropriate.
iv. Identification of patients for reassessment of readiness to enter the transition process if deemed unready for entry at first assessment.

b) Secretarial

i. Supporting effective running of the process by sending out relevant documentation (Initial transition pack).
ii. Typing and sending of relevant correspondence to families and professionals.
iii. Collation and distribution of relevant documentation relating to individual patients' care to support summary documents e.g. radiology reports, histology reports etc. where clinical portal is not available.
iv. Liaison with colleagues across teams to organise transition clinics.

4.2 Paediatric Nurse

i. Initial assessment of suitability for entry into transition process involving the patient. (Transition/Transfer Pathway: Appendix A)
ii. Completion of nursing summary section. (MDT Transition summary: Appendix D)
iii. Participation in transition clinics.
iv. Key worker for the family, providing support and acting as first point of contact throughout process.
v. Discussion with young person and family regarding the transition process discussions of differences between paediatric and adult care, helping to set targets and goals.
vi. Complete young person's transition assessment sheet (Appendix C) and set goals with a plan at varying stages of the transition process.
vii. Formal review of readiness to progress between stages of transition.
viii. Disease and lifestyle education.
ix. Exploring and addressing issues surrounding poor adherence to treatment or failure to attend clinic sessions.
x. Engagement with education and/or social services to ensure effective transition for young people.
xi. Liaison with adult GI nurse and community team/services regarding handover of care.

4.3 Adult Nurse

i. Participation in joint transition clinics.
ii. Provision of information describing adult model of care – information about hospital, details of outpatient clinics, inpatient facilities, endoscopy arrangements.
iii. Acceptance of responsibility for taking on role in patient support, communication, coordination and completion of documentation pertaining to medication and care delivery.

4.4 Paediatric Medical staff

i. Initial assessment of suitability for entry with nursing staff. (Appendix A)
ii. Completion of medical summary section. (Appendix D)
iii. Participation in joint transition clinics.
iv. Correspondence to other healthcare professionals regarding transition arrangements and individual progress.
v. Correspondence to other healthcare professionals from jointly held transition clinics in paediatric centre.

4.5 Adult Medical

i. Participation in joint transition clinics.
ii. Correspondence with other healthcare professionals from jointly held transition clinics in adult centre.

4.6 Paediatric Dietetics

i. Completion of nutritional summary detailing nutritional needs and support provided when relevant. (Appendix D)
ii. Participation in joint transition clinics for relevant young people.
iii. Correspondence and liaison with adult dietetics.

4.7 Adult Dietetics

i. Liaison with paediatric colleagues.
ii. Participation in joint transition clinics for relevant young people.
iii. Acceptance of responsibility for taking on role in support of nutritional needs and ensuring delivery of appropriate feeds and ancillary equipment.

4.8 Psychology

i. Provision of psychological support for young person and family through transition process where necessary.
ii. Completion of the psychology summary section. (Appendix D)
iii. The identification and management of serious psychopathology (including referral on to Psychiatry if required) after initial referral from another member of the MDT.
iv. Support and guidance for multidisciplinary team in guiding young person through transition.
v. Liaison with community or adult mental health professionals as required.

5. BODY OF POLICY

(See Transition/Transfer Pathway, Appendix A)

5.1 Planning for Transition

Criteria for consideration of entry into Transition Process for Young Person with chronic GHN disease:

a. Aged at least 14 years
b. Diagnosed for at least 1 year
c. Young person physically and psychologically mature
d. Not acutely unwell
e. Not within 6 months of major surgery

Eligible patients and relevant adult GI centre are identified by data manager and clinical staff informed.

5.2 Initiation of Process

- Multidisciplinary team discussion to confirm appropriate timing of transition for individual patient [17, 18, 19].
- Correspondence to be sent to young person and copy to parent's/carers (see standard letter, Appendix B).
- Identify most appropriate adult team young person to transition to (taking into account patient preference, geography, local expertise, personnel, facilities and willingness to engage in the transition process).
- Inform multidisciplinary team and all multi agency staff involved in patient care of purposed transition (i.e. gastrostomy nurses, community staff, such as the GP, Community Children's Nurses, hospital education service, social work, independent advocacy worker)[18].

5.3 Early Transition

<u>Discussion of Process</u>

- Formal individualised discussion with young person and parents/carers held in outpatients clinic in the paediatric setting
- Ensure the following areas covered:
  - Philosophy of care

- Nature of process
- "Key Worker" on paediatric and adult teams 17,13.
- Disease-specific Transition documents (e.g. Crohn's and Colitis UK, CLDF, Half-PINNT etc)

Assessment of Young Person's Readiness

A rolling young person's assessment tool will be utilised. This is completed with the young person and will aid assessment of readiness to commence the transition process (See Appendix C).

Roles and responsibilities

Explore the following with topics and agree goals for the young person to achieve before the next stage in transition.

a) Self-advocacy
   Encourage the young person to take an active role by having more responsibility and managing their condition. Examples include: -
   - Ability to describe their condition
   - Ability to ask questions during clinic visits
   - Ongoing encouragement of parents/carers to engage in disease management, whilst facilitating increased autonomy[15].

b) Independent health care behaviour.
   Increasing knowledge of medication.
   Promote confidence within young person to seek help in event of health concerns.
   Ensure understanding of the principles of confidentiality[15].

c) Sexual Health
   Discussion of changes associated with puberty.
   Ensure accessibility of appropriate information and advice about puberty, sex and sexuality[15].

d) Psychosocial Support
   Allow the young person and their parents to discuss feelings about the transition process and worries about the future.
   Explore young person's support network – friends, family etc[15].

e) Educational and Vocational planning
   Discuss responsibilities at home.
   Discuss any restrictions (whether real, imagined, self-imposed, imposed by parents etc) that affect the young person's educational and recreational activities[17].

f) Health and Lifestyle
   Discuss issues surrounding smoking, drinking and drugs on health and consequences of risk taking behaviour.
   Discuss specific issues of impact on young person's condition and general health[17].

Activities

Action plan and goals to be set – agreed between young person, parents and health care professionals (Parents may need additional support and guidance to adjust to the transition process[14]. The working group facilitated patient and parents focus groups and

the WoSPGHaN findings mirrored Knapp et al 2013 findings; that parents need extra support during this process.

Formal disease education.

5.4 Mid-Transition

Discussion of Process

Provision of written information about adult team and hospital.
Provision of team contact details. (Appendix E)

Assessment of Young Person's Progress

Assessment (by young person's rolling assessment tool, see Appendix C) of success of disease education and psychological readiness to proceed through the transition process[6].

Roles and responsibilities

a. Self-advocacy
   Ensure accessibility of information about their condition, e.g. support groups, Internet or condition-specific organisations.
   Promote self-advocacy and assume increasing responsibility for own health.
   Examples include:
   - Entering clinic room without parent/carer
   - Ability to describe own health needs and concerns
   - Increasing knowledge of medication and other treatments
   - Ability to book own appointments, order repeat prescriptions etc[15].

b. Independent Health Care Behaviour
   Continue to facilitate increasing autonomy, e.g. maintaining a personal health record which incorporates all aspects of their disease process.
   Ensure young person knows when and how to get emergency/medical help.
   Ensure the patient understands the different model of care in children's and adult services[15].

c. Sexual Health
   Providing opportunity for the young person to ask questions about the impact of the condition and/or medications on sexual health, e.g. affect on fertility?
   Discuss possible impact on pubertal development of young person's condition[15].

d. Psychosocial Support
   Encourage young person to join a social group, such as a club or youth group[15].
e. Educational and Vocational planning

   Discussion re school, favourite subjects, and any career plans or ideas.
   Encourage young person to seek appropriate careers counselling.
   Explore possibilities for work experience[17].

f. Healthy Lifestyles
   Discussion regarding restrictions on mobility caused by young person's condition.

Discussion about body image.
Discussion around support for low mood, stress or anxiety[17].

Activities
Clinician should have formal discussion with the young person regarding goals and objectives to be achieved prior to completion of the transition process.

Involve the parents in empowering the young person in developing independence and assuming responsibility. This in addition will help the parents to 'let go' and have confidence in their child's ability to self-manage parts of their own care[6, 20].

5.5 Late Transition

Flexibility is especially important. This is particularly the case when considering the time of late transition as not all young people are ready for this at the same age/time. It means taking into account each individual's cognitive and emotional state, their physical development and their health[4,15]. Consideration should also be given to their stage of education e.g. avoiding exam times.

The first joint appointment to be held with adult GHN team: this should ideally be within the familiar setting of the Paediatric Outpatient Department (either in RHC Glasgow or in the DGH Outreach clinic). Consideration should be given to lengthening consultation times, for the transition process beyond those in either the children's or adult services.

<u>Discussion of Process</u>

<u>Assessment of Young Person's Progress</u>
Review young person's rolling assessment documentation tool (Appendix C).
Assess individuals knowledge of own condition, self-efficacy in disease management and psychological readiness to move to adult care [21, 15].

Roles and responsibilities
a) Self-advocacy
   Explain all the available adult care options. Provide details about relevant adult care providers, including the differences between paediatric and adult care. If appropriate, help young person to choose an adult care provider and arrange visits[15].

b) Independent Health Care Behaviour
   Facilitate increased independence and responsibility for health. This might include use of a personal health record book, incorporating appointment times, health information, medication, treatments and details of health providers[15].

c) Sexual Health
   Discussion of young person's sexual capabilities; including physical capability, fertility, safe sex and any associated genetic issues.

   Have discussion of the impact of their condition on pubertal development and their sexual health[15].

d) Psychosocial Support
   Encourage young person and their parents to set goals.

Identify any need for assistance in personal care.
If young person's condition is potentially life-shortening, identify any need for help in dealing with this[15].

e) Educational and Vocational planning
Discussion of employment options - what kind of work do they want to do? Are there any restrictions, e.g. on number of hours young person can work or exclusions their health condition may place on career options? Is there an opportunity for a work experience placement?

Discussion of the health care benefits available, for example, the Disability Living Allowance[17] (DLA).

If young person plans to go to college or university, discuss the implications of this choice.

f) Healthy Lifestyles
Ensure young person has an awareness of who they can contact should they experience low mood, stress or anxiety.

Give young person the opportunity to discuss any feelings of low mood, depression, or problems adjusting to or managing their condition[17].

A second joint appointment should be held with adult GHN team where applicable. This should ideally be within the adult outpatient department where the young person will subsequently be seen. This clinic should occur 3-6 months after the first joint appointment.

5.6 Transition of care

Care to be handed over to the adult team if agreement by young person, paediatric and adult teams. The transition is a lengthy process which should continue into adult care i.e. it does not stop at the point of consultant handover.

A new key worker is identified for the young person (usually the adult GI nurse), that is a named individual who has responsibility for co-ordinating the young person's care. They can be approached by the young person or family and also have the responsibility for collaborating with other health professionals.

If the young person does not demonstrate readiness for transfer to adult care (or if the young person becomes acutely unwell, requiring significant escalation or alteration in treatment) he/she should remain in the transition process for a further 6 months prior to reassessment[14] (see 5.5)

6. Implementation

The pathway in Appendix A is not intended to be prescriptive but to support the development of transition processes in the Chronic Gastroenterological, Hepatological and Nutritional diseases from children's to adult health services.

Each medical speciality should adapt its own transition process based on the appropriate pathway, taking into account the principles of transition within this document.

7. Transfer of care

It is not always possible to have a joint transition clinic for the young person to attend due to the geographical situation and clinical resources for some specialities within gastroenterology. In this situation the young person should follow the transition process, until 'ready to move to adult services' whereby they will then be transferred at this stage. See the transfer pathway in Appendix A. Again, this is not intended to be prescriptive but to support the development of the transfer processes in the Chronic Gastroenterological, Hepatological and Nutritional diseases from children's to adult health services.

Note: a safety net appointment should be kept in the paediatric setting, until confirmation is obtained by the patient of an equivalent appointment in the adult setting.

8. Review

i. Audit
   It is recommended that the transition process be subject to regular audit to ensure that the policy is being accurately and appropriately adhered to[15].

ii. Assessment of User Satisfaction
   It is further recommended that views are sought from individuals progressing through the transition process e.g. via use of satisfaction surveys, feedback documentation and/or focus groups[16].

iii. Formal Review
   Review date: October 2016
   Regular review must take account of:
   - the evaluation or audit of the current policy
   - changes to organisational and national policy and context
   - the ongoing requirements for the policy

The lead manager is responsible for ensuring that review takes place at the appropriate time. The heads of administration through the policy management system will ensure that lead managers receive a prompt at the appropriate date.

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APPENDIX A

WOSPGHAN Transfer Pathway

Stages: Pre Early Mid Late

Box 1
- Aged at least 14 years
  Been diagnosed for minimum of 1 year
- Young person physically and psychologically mature (by self-assessment, with team agreement)
- Not acutely unwell
- Not within 6 months of major surgery

>14 years of age

Does the young person fulfil criteria for entry into Transition Process?
(See Box 1)

Review in 6 months

Yes

No

- Outpatients clinic
- MDT review
- Discussion with young person and parent/guardians

Transition Assessment
- Set objectives: 6-12 months
- Make Action Plan
- Letter to young person with booklet

Box 2
- Aged at least 16 years
- Disease as stable as possible
- Physically post-pubertal
- Psychologically mature (by self and team assessment)
- Disease education received
- Able to assume roles and responsibilities for self-efficacy
- Diagnosed for at least 1 year

Outpatient Clinic Appointments
- Ongoing assessment over 6-12 months
- Set objectives for next 6 months
- Ongoing education

No

Ready to move to Adult Services?
(See Box 2)

Yes

TRANSFER

Complete Paperwork
- Medical
- CNS
- AHP

Arrangements for Handover of drug/ care arrangments eg BUPA, CNS Review, Homeward etc

- Send out transfer letter and appropriate document to Adult Colleagues
- If applicable, arrange safety net Paediatric appointment and parent/guardians

TRANSFER COMPLETE

APPENDIX A

WOSPGHAN Transition Pathway

Stages: Pre Early Mid Late

Box 1
- Aged at least 14 years
  Been diagnosed for minimum of 1 year
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- Not within 6 months of major surgery

>14 years of age

Does the young person fulfil criteria for entry into Transition Process?
(See Box 1)

Review in 6 months

Yes

No

- Outpatients clinic
- MDT review
- Discussion with young person and parent/guardians

Transition Assessment
- Set objectives: 6-12 months
- Make Action Plan
- Letter to young person with booklet

Box 2
- Aged at least 16 years
- Disease as stable as possible
- Physically post-pubertal
- Psychologically mature (by self and team assessment)
- Disease education received
- Able to assume roles and responsibilities for self-efficacy
- Diagnosed for at least 1 year

Outpatient Clinic Appointments
- Ongoing assessment over 6-12 months
- Set objectives for next 6 months
- Ongoing education

No

Ready for late transition?
(See Box 2)

Yes

Complete Paperwork
- Medical
- CNS
- AHP

1st joint appointment at Paediatric Outreach Clinic

Arrangements for Handover of drug/ care arrangments eg BUPA, CNS Review, Homeward etc

2nd joint appointment preferably at Adult Clinic

Clinically stable and ready to move to Adult Services?

No

Yes

Final handover to Adult Services

MIS 264208-2

Appendix B
Standardised patient letter

WoSPGHaN
West of Scotland Gastroenterology, Hepatology and Nutrition Network
www.wospghan.scot.nhs.uk

NHS SCOTLAND

Patient Address

Tel:

Date:

Ref:

Dear (patient name)

RE: TRANSITION PROCESS

As discussed at your last clinic appointment, we would like you to start the transition process to adult services. This process can take up to three years and aims to make the transition as stress-free as possible.

To prepare for any discussion it would be helpful if you could start organising your own medicines. This includes:

- knowing the names and dosages of your medication and
- how to get prescriptions from your GP

Some young people find it helpful to write this information down in their phone, on paper or in a medication book to help jog their memories. It can also be useful to write down any questions you may want to ask. (IN PROGRESS)

When you feel ready, we would like you to come into the clinic room for your appointments by yourself so that you get used to answering any questions on your own. If you want, you can invite your parent/carer to come in afterwards for a summary of the discussion.

We understand that aspects of transition can be difficult at first, but these are the first steps to gaining more independence and moving to adult services. If you have any questions, or would like to discuss this in more detail, please contact us on **(insert telephone number)**.

Kind Regards

Yours sincerely

cc Parents

Appendix C

West of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network

WoSPGHaN NHS SCOTLAND

www.wospghan.scot.nhs.uk

Gastroenterology Young Person Transition Assessment and Plan 14 years +

PATIENT LABEL

Tel Number: .....

Parent/Guardian: .....

Parent/Guardian: .....

Paediatric Consultant: .....

Paediatric CNS: .....

Medical History: .....

.....

.....

.....

Date Started:		Transition Hospital:
Adult Physician:		Specialist Nurse (adult):
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:
Date:	Stage:	Seen by:

Date completed: ..... Signed (Staff): .....

Date of final transition: ..... Signed (Young Person): .....

Age:

Early Transition Assessment with Young Person

Actively *Discuss* and *Plan* the following with the young person

		Discussed	Flag	Date
Self Advocacy	• *Learn about the transition process* • *Can describe own health condition and treatments* • *Can independently ask questions during clinic visit* • *Makes next clinic visit with support* • *Starts to be seen alone for part of the clinic visit* • *Knows who to contact if not feeling well*			
Independent Behaviour	• *Begins to learn names, doses and how often to take own medication* • *Starts to learn the reason for taking medicine and how they work* • *Chooses a method to remember to take medication* • *Knows where and how to access help for any medical concerns with support*			
Sexual Health	• *Discuss body image, changes in appearance due to puberty or/and medication* • *Discuss issues around puberty and how their health condition may impact on this* • *Identify any concerns regarding puberty or changes in the body*			
Social Supporters	• *Can identify people to talk to if feeling sad or fed up (e.g family, friend, school teacher, nurse)* • *Is aware of the existence of online support e.g. Crohn's & Colitis UK/CLDF websites APPs and events* • *Discuss the transition process with family/carers* • *Discuss the family's changing role across the transition process*			
Education/ Vocation	• *Discuss school - attendance, strengths, goals and concerns* • *Identify any areas where condition may be restricting activity*			
Healthy Lifestyles	• *Discuss the importance of healthy eating, and how it relates to condition* • *Discuss the importance of exercise on general health and condition* • *Discuss issues such as smoking, drugs and alcohol and how they can affect condition*			

Age:

Mid Transition Assessment with Young Person

Actively *Discuss* and *Plan* the following with the young person

		Discussed	Flag	Date
Self Advocacy	• *Feels confident to be seen on own during some/all clinic visits* • *Is able to identify and access information and support on condition i.e. support groups* • *Describes condition accurately in own words* • *Knows who is involved in their health care (names professionals) i.e GP* • *Participates in decision making and consent*			
Independent Behaviour	• *Keeps a personal record book to keep track of information and care related to their condition i.e. appointments, medication, blood monitoring* • *Responsible for obtaining own presciption* • *Able to book next clinic appointment independently* • *Able to access help when unwell independently* • *Understands differences between paediatric and adult services* • *Describes medication and reason for them* • *Adheres to medication regime and describes any concerns (e.g. side effects)* • *Describes investigations and rationale for them*			
Sexual Health	• *Describes body issues in relation to compliance of medications* • *Names person/place reliable for accessing accurate information on sexual health* • *Can identify sexual health concerns and asks appropriate questions* • *Discuss issues around sexual health including opportunity to ask questions around impact of condition/medication/ contraception/pregnancy and any effects on fertility* • *Identifies factors concerning the impact of pubertal development on their condition*			
Social Supporters	• *Can identify people to talk to if feeling sad or fed up (e.g family, friend, school teacher, nurse)* • *Is aware of the existence of online support e.g. Crohn's & Colitis UK/CLDF websites APPs and events* • *Can identify someone to talk to if having difficulties with any part of the transition process*			
Education/ Vocation	• *Discuss ideas about future plans and goals* • *Discuss any concerns about how their condition may impact on these*			
Healthy Lifestyles	• *Understands the importance of exercise on general health and condition* • *Understands the importance of following dietary recommendations/restrictions* • *Able to discuss issues such as smoking, drugs and alcohol and how these can affect general health and condition* • *Aware of who to contact should they experience low mood, stress or anxiety*			

Age:

Late Transition Assessment with Young Person

Actively *Discuss* and *Plan* the following with the young person

		Discussed	Flag	Date
Self Advocacy	• *Discusses adult care options and has identified hospital transitioning to* • *Confidently knows difference between adult services and paediatric* • *Confident to be seen alone during clinic visits and is able to convey important information onto parent/carer* • *Aware of their rights to information, privacy and be wholly involved in decision making* • *Informed of who will be involved in their adult care and been provided with relevant information* • *Aware information will be transferred to adult services*			
Independent Behaviour	• *Reviews own personal health care needs* • *Demonstrates knowledge of medication, refilling prescriptions and booking appointments* • *Aware of the impact of poor adherence to treatment* • *Can identify GP and adult specialist team for their ongoing health care needs* • *Attends joint Paediatric/Adult clinic* • *Prepares for final transition* • *Explores ways of getting to the adult clinic i.e. transport, bike, with parents*			
Sexual Health	• *Can identify sexual capabilities including physical, fertility, safe sex and any associated genetic issues* • *Understands risks of sexual behaviour re: condition, contraception, sexually transmitted diseases and pregnancy* • *Discusses whether medication can affect pregnancy* • *Knows where to get advice re: sexual health and sexually transmitted diseases* • *Knows where to get advice if becomes pregnant*			
Social Supporters	• *Confident that they can identify people to talk to if they experience a change in their mood e.g. depressed* • *Is aware of the existence of online support e.g. Crohn's & Colitis UK/CLDF websites APPs and events* • *Can identify someone to talk to if having difficulties with final part of the transition process*			
Education/ Vocation	• *Aware of potential impact of condition on future career/ education plans* • *Plan in place to minimise impact* • *Aware of any healthcare benefits available (if applicable)*			
Healthy Lifestyles	• *Able to identify and follow dietary recommendations* • *Aware of how smoking, drugs and alcohol can affect general health and condition* • *Able to identify plan for needs/issues around being away from home (e.g. living away from home/holidays)* • *Recognise and aware of who to contact should they experience low mood, stress or anxiety*			

ACTION PLAN for Young Person

Professionals notes: Action plan to be discussed, agreed and formulated with young person

EARLY TRANSITION	
MID TRANSITION	
LATE TRANSITION	

Transition - Young Person's Parent/Guardian

Transition Plan: Subjects discussed with parents/guardians as highlighted

		Discuss	Date
Self Advocacy			
Independent Behaviour			
Sexual Health			
Social Supporters			
Education/ Vocation			
Healthy Lifestyles			

West of Scotland Paediatric Gastroenterology, Hepatology and Nutrition Network

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MDT TRANSITION SUMMARY

Consultant

Contact Details:

Patient Name: _____CHI_____

Telephone number: Home_____ Mobile _____

Address: _____

_____

GP:_____ Other Paediatric Specialities Involved

Address: _____ Name & contact numbers:

_____ _____

Telephone_____ _____

Paediatric nurse: Paediatric Gastroenterology/Consultant

Name & Contact details: Name & contact details:

_____ _____

Adult nurse Adult Gastroenterology Consultant

Name & Contact details: Name & contact details:

_____ _____

Location of clinic: _____

Primary Diagnosis: _____

Co-morbidities: _____

Age at diagnosis: _____

Weight: _____ Weight centile: _____

Height: _____ Height centile: _____ Tanner stage: _____

Surgeon informed of transition/transfer: YES / NO

Surgery: **Dates**:

_____ _____

_____ _____

_____ _____

Most recent investigations

Endoscopy/colonoscopy: Date: Finding:

Imaging: Date: Finding:

Biopsies: Date: Finding

DEXA: Date: Finding:

Other: Date: Finding:

Blood monitoring arrangement: **Hospital / GP**

Any other information: **Refer to detailed transition letter**

Current Drug therapy:

Drug name	Dose	Route	Frequency	Level range
Sytron				
Calcium Sandoz				
Ferrous Fumaratre				
Abidec				

Previous relevant drug therapy:

Drug name	Date on	Date off	Reason for discontinuation

Allergy/previous drug reactions:

_____

_____

Any significant clinical laboratory results:

_____

Documents attached:

Growth chart Y/N Pathology results Y/N Dexa Scans Y/N

Imaging reports Y/N Lung function Y/N Other _____

Name: _____ Designation: _____ Date: _____

Nutrition

Enteral nutrition

Preparation	Route	Volume	Frequency	Administration

Additional information:

Name: _____ Designation: _____ Date: _____

Device

Device	Type	Size	Length	Change frequency	Insertion date
Nasogastric tube					
NJ tube					
GJ tube					
Surgical jejunal tube					
Gastrostomy					

Name: _____ Designation: _____ Date: _____

Parental Nutrition Regime:

Central venous device:

Type: _____ Size: _____ Length: _____

Site: _____ Date inserted: _____

None standard Pharmacy: Y/N

Name: _____ Designation: _____ Date: _____

Nursing

Adherence with compliance: **Yes / No**/variable _____

Immunisations:

Vaccine	Date administered	Titre	comment
Hepatitis B			
Varicella			
Childhood vaccines			
HPV			

Smoking/alcohol: _____

Family background: _____

_____

Social work involvement: **Y / N** Details: _____

_____

Education/employment: _____

Stoma Nurse: **Y / N** (If yes, see additional information)

Stoma type: Appliance product: Flange Size: Bag size:

Supplier: _____

Any additional information

Name: _____ Designation: _____ Date: _____

Psychology: **Y / N**_____

Psychology

Name: _____ Designation: _____ Date: _____

Appendix E
Adult hospital information card

Transition Information Card

Hospital ……

Consultant ……

Clinic ……

Specialist Nurse/Dietitian ……

Contact Telephone Number ……

Additional Information

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……

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……

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This guideline has been created by WoSPGHaN Transition working group within Paediatric Gastroenterology.

WoSPGHaN

West of Scotland Gastroenterology, Hepatology and Nutrition Network
www.wospghan.scot.nhs.uk

If you would like more information, visit the website: www.wospghan.scot.nhs.uk

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