

APPENDIX

Task groups/Topics and responsible authors

Introduction and methods (JFL), Background (JFL), Biological issues: Aim (DSS, RS), Disease phenotype (SC, IH), Heredity and genetic risks (IH), Differences in child and adult health care (SC, SK, SH), Transition aims (SC, RT), Need for extra dietary support in the adolescent and young adult (SK, MLM, DSS), The actual transfer of care (PHRG, MLM, DSS), Factors influencing a successful transition (CC, SK, NR, RS), E-health (MLM, RS), Communication issues (NR), Adapting adult health care to suit the young adult (JFL, NR), Issues to discuss in a transition setting (JFL, CC, RS), Special cases (PHGR, RT), Primary care involvement (JAM, PH, LA), How current guidelines differ (IH, MLM, DSS, SH), How to follow up the young adult with CD with or without prior biopsy (PHGR, KL, NR, RT, SH), Histology in children and adults (MW), NCGS (KL, MW, SH), Follow-up: how often? (IH, KL, DSS), Bone mineral density (KL, NR), When the patient wants a gluten challenge (CC, SK), Insurance issues (PHGR, JAM), Growth and puberty (NR), Future research (RT, CC), Emotional maturity (JFL), Transition models (JFL), Complications and comorbidities (JFL), Discussion (JFL), Appendix (JFL).

Strength of recommendations (GRADE)

The quality of evidence for each statement was graded as high, moderate, or low (A, B, C)¹⁸.

“Transition document”

Young adults with coeliac disease should be provided with a medical summary of their childhood (“the transition document”) and on-going health issues.

Purpose	Content
<ul style="list-style-type: none">• To serve as an important means of communicating medical concerns with an accepting adult physician.• To ensure that the patients maintain awareness of and input into the issues viewed as most critical in their health¹⁴⁵	<ul style="list-style-type: none">• What was the basis of the coeliac diagnosis?• Has the child suffered from signs and symptoms of malabsorption before starting a GFD?• Serological and biopsy results before starting a GFD?• Serological and biopsy results after starting a GFD?• Has the patient been screened for other diseases during childhood (including type 1 diabetes and autoimmune thyroid disease)?• Has the patient any signs of other comorbidities?• Did the patient follow the diet since diagnosis (adherence)• Percentiles for height, bodyweight, body mass index, pubertal development

GFD, Gluten-free diet

Literature search

Medline (Ovid)

1. exp Celiac Disease/
2. exp Glutens/
3. (celiac* or celiak* or coeliac* or coeliak* or gluten or non-tropical sprue or nontropical sprue).ti,ab,kw.
4. or/1-3
5. exp "Continuity of Patient Care"/
6. Patient Transfer/
7. exp Patient Care Planning/
8. exp Transition to Adult Care/
9. (transition* or transfer*).ti,kw.
10. ((transition* or transfer*) adj10 (care or service* or centre* or centre* or clinic* or facility or facilities or unit* or department* or patient*)).ab.
11. (continuity adj3 (care or health care or healthcare or treatment* or therapy or therapies or patient* or doctor-patient or nurse patient)).ti,ab.
12. or/5-11
13. 4 and 12
14. remove duplicates from 13

EMBASE

- #11
#4 AND #10
#10
#5 OR #6 OR #7 OR #8 OR #9
#9
(continuity NEAR/3 (care OR 'health care' OR healthcare OR treatment* OR therapy OR therapies OR patient* OR 'doctor-patient' OR 'nurse patient')):ab,ti
#8
((transition* OR transfer*) NEAR/10 (care OR service* OR centre* OR centre* OR clinic* OR facility OR facilities OR unit* OR department* OR patient*))ab
#7
transition*:ti OR transfer*:ti
#6
'transition to adult care'/exp
#5
'patient care planning'/exp
#4
#1 OR #2 OR #3
#3

celiac*:ab,ti OR celiak*:ab,ti OR coeliac*:ab,ti OR coeliak*:ab,ti OR gluten:ab,ti OR
'non-tropical sprue':ab,ti OR 'nontropical sprue':ab,ti

#2

'gluten'/exp

#1

'celiac disease'/exp