

Check list for physicians informing newly diagnosed coeliac patients and their caregivers

Pictograms for the patients in lay terms provided by ESPGHAN in different languages may support you. We recommend to tick items discussed. Sign with date and name and add the check list to patient file.

Explain findings to confirm the diagnosis according to the ESPGHAN guidelines	<input type="checkbox"/>
<ul style="list-style-type: none"> Serology, endoscopy/histopathology (if done), other results 	
What is Coeliac Disease (CD)?	
<ul style="list-style-type: none"> Immune mediated auto-immune disease in genetically predisposed individuals, triggered by intake of gluten and related proteins from wheat, rye, barley and related grains. Treatment: Gluten free diet (GFD) Many organs can be affected, the mucosa of the small bowel being one of them Possible consequences of mucosal damage on absorption of nutrients/minerals Unspecific symptoms including, but not limited to those from the bowel 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Causes	
<ul style="list-style-type: none"> Interplay of genes, gluten intake and possibly other environmental factors (not yet known) result in a lifelong auto-immune-disease Risk of developing other HLA related auto-immune-diseases (e.g., thyroid, liver); this is not related to adherence to the diet Risk of long-term complication if adherence to GFD is insufficient, regardless whether symptoms occur after gluten intake or not 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Reassure on excellent prognosis, take guilt and anxiety from parents	<input type="checkbox"/>
Therapy	
Medical:	
<ul style="list-style-type: none"> CD is chronic, cannot be cured, but it can be very well treated Life-long gluten free diet with strict adherence Drugs may be available in the future 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Psychosocial:	
<ul style="list-style-type: none"> Reorganizing household, prevent cross-contact contamination etc. Meals in day care and school Information for family and friends, teachers Emotional coping (GFD not easy for child; psychological support if needed) 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Goal of therapy:	
<ul style="list-style-type: none"> Healing of mucosa and chronic inflammation Normalization of auto-antibodies within 1 (to max 3 years) Surveillance of diet & growth & development Strengthening of self-confidence, handling the disease/diet, outing (disclosing to others having CD) 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
What next?	
<ul style="list-style-type: none"> Initial consultation & education by dietician or other health care professionals competent on GFD 1st follow up: after 2-3 months (focused blood test in case of any deficiencies) 2nd follow up after 5-6 months including blood test for TGA 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Long-term follow up for monitoring of disease, diet, growth, development	
<ul style="list-style-type: none"> Control TGA every 6 months until negative, thereafter 1x/year until transfer to adult care 	<input type="checkbox"/>
Importance of patient information and empowerment	
<ul style="list-style-type: none"> Provide written information, links to informative sites & contacts to patient organization Provide Link to e-learning (www). 	<input type="checkbox"/> <input type="checkbox"/>
Recommend screening of first-degree relatives for CD	<input type="checkbox"/>
Hand out document with results of confirmed CD diagnosis	<input type="checkbox"/>
Date:	
Name of physician:	