COELIAC AWARENESS - INFORMATION FOR SCHOOLS

Do you have students in your school who have Coeliac Disease?

Recent studies about Coeliac Disease indicate that about 1 in 70 people in New Zealand will have the disease but probably 80% of these people will not be aware of this condition.

What is Coeliac Disease?

Coeliac Disease, is a genetically based life long intolerance to dietary gluten. If gluten is eaten, damage to the lining of the small bowel occurs, and food is not absorbed properly. Even small amounts of gluten in food may affect people with Coeliac Disease. Coeliac Disease can be diagnosed at any age from tots to the elderly. Ten per cent of diagnosed Coeliacs have family members who are subsequently found to also be Coeliacs.

Symptoms of Coeliac Disease:

Symptoms include diarrhoea, anaemia, poor growth, weight loss, irritability, chronic fatigue, cramps, muscle wasting and bloating. A Coeliac child may feel miserable or depressed. The symptom of weight loss could be confused with anorexia, especially in teenage girls.

What is Gluten?

Gluten is a protein found in any food made from wheat, barley, rye and oats. There are many obvious foods that contain gluten such as bread, cakes, pasta, crumbed and battered food, as well as many types of prepared and commercial foods where gluten may not be an expected ingredient. A Coeliac is encouraged to follow the rule 'If in doubt, leave it out'.

Treatment:

Once diagnosed, treatment consists of strict adherence to a gluten free diet — for life. Symptoms usually disappear within three months of eating a gluten free diet. After this time, a child should feel well and most will then have the same sort of energy levels as other children. However, it is important to remember that Coeliac Disease cannot be cured — Once a Coeliac, always a Coeliac.

What happens to a Coeliac Child if gluten is eaten: Following ingestion of food containing gluten, a child may have symptoms within 20 minutes, e.g. stomach pain, diarrhoea, headache, irritability, vomiting — they could have one or more of these.

Sometimes these symptoms are delayed and they can last for a number of days before subsiding.

Anaphylactic shock should not generally occur, unless the child has another disorder, eg peanut allergy.

Implications for Teachers

Primary

- Liaise with the parents to understand the child's needs.
- Be aware that a Coeliac child must <u>never</u> swap food with the other children.
- Never believe that "surely a little bit won't hurt". It can, and it does.
- Some children report being teased about their "funny sandwiches". A teacher can help to discourage such behaviour.
- Send a note home in advance concerning any food or sweets being distributed during special events: Parents can then arrange a "treat" to be available, so the child does not feel left out.
- The teacher should be familiar with the needs of the child in their classroom. Depending on age, a unit on food could include information about Coeliac Disease and other health issues, such as diabetes and peanut allergies, to educate the other children.
- Trips and camps can be problematic. Please notify the child's parents in plenty of time so that they can bring their own food.
- Sudden diarrhoea can be a problem for a Coeliac –
 permit the child to go to the toilet as soon as she or
 he asks permission.

Secondary

- Teenagers sometimes feel considerable peer pressure to eat the same as everyone else.
 Teachers should support the students safe choices.
- Students can feel pressure during Food Technology classes. Please support them and allow substitutions where possible. There are many tasty gluten free recipes available.
- Consider whether the tuck-shop offers anything for the Coeliac student.
- School purses should be notified and be familiar with symptoms and treatment.

HOW CAN THE COELIAC SOCIETY HELP YOU?

The NZ Coeliac Society provides advice and information about the Coeliac Disease, gluten free foods and recipes, effects of gluten contamination and other educational material etc. Refer www.coeliac.org.nz

Regional Support Groups give information and support to Coeliacs and their families/ caregivers. The Wellington Support Group provides coverage from Waikanae and Upper Hutt south. Coordinator is Bill Darnell - darnell@paradise.net.nz or 04 232 4852

COELIAC AWARENESS - INFORMATION FOR PRACTICE NURSES

Do you have patient who persistently present with:

- Unexplained tiredness
- Unresolved anaemia
- Abdominal discomfort

Your patients could be suffering from Coeliac Disease. Please take 5 minutes to read this and you could improve their quality of life dramatically by assisting in their diagnosis.

What is Coeliac Disease?

Coeliac disease is a medical condition and is a permanent intestinal intolerance to dietary gluten. In a Coeliac the cells of the small bowel are damaged by the consumption of any gluten causing a flattening and inflammation of the villi (finger-like projections from the lining of the intestine). The absorptive surface area of the bowel may be seriously impaired leading to deficiencies in vitamins, iron, folic acid and calcium. Sugars, proteins and fats are sometimes poorly absorbed as well. Untreated, this can result in severe diarrhoea and malnutrition and increased risk of other diseases including lymphoma and osteoporosis.

What is the Cause?

Coeliacs are sensitive to gluten which is found in wheat, rye, barley, and oats. These react with the small bowel lining, damaging it and causing loss of effective absorption surface area of the villi. Both genetic and environmental factors play important roles in Coeliac Disease.

How common is Coeliac Disease?

Coeliac Disease has really only been given recognition in recent years and studies indicate that about 1 in 70 in New Zealand will have the disease but probably 80% of these people will not be aware of this condition. This means that about 65,000 people in New Zealand will be coeliacs but about 52,000 will not know be aware of that. Coeliac disease will likely be affecting at least some of your patients.

Possible Signs of Coeliac Disease include:

- Iron, folate, or B12 deficiency
- Anaemia
- Tired all the time
- Diarrhoea, constipation or combination
- Abdominal pain, indigestion, bloating, wind
- Unexplained gastrointestinal symptoms
- Dermatitis Herpetiformis

Likelihood of being a coeliac increases if the patient also has:

- Coeliac disease in the family
- Thyroid disease
- Type I diabetes mellitus

- Down's Syndrome
- Abnormal liver tests
- Osteoporosis
- Undefined neurological disorder/epilepsy
- Infertility/recurrent miscarriage.

Testing for Coeliac Disease:

Screening for coeliac disease can be done by a simple blood test. If this test is positive, it is important that your patient is then referred to a Gastroenterologist to confirm the diagnosis by a biopsy.

The patient should not start a gluten-free diet until the diagnosis has been undertaken.

How is the Condition Treated?

The only treatment for Coeliac Disease is a strict, lifelong gluten free diet. By specifically removing the cause of the disease, this treatment allows the abnormalities, including that of the bowel lining to recover and will reduce the risk of developing other associated diseases. Pharmacist and General Practitioners should be informed that the resident is a celiac and is gluten intolerant. All medications supplied must be checked to ensure they are gluten free.

Long term risks from Coeliac Disease

Long-term risks includes osteoporosis, poor growth, infertility, miscarriage, iron deficiency, an increase in the overall mortality rate, and twice the risk of GI tumours. There are potentially serious consequences if it is not diagnosed as soon as possible.

How can we help your patients once diagnosed?

The Coeliac Society gives information and support to coeliacs and their families. Advice and information is available about the condition, gluten free diet and ingredients, where to buy, recipes and cooking, overseas travel, educational material etc. Refer www.coeliac.org.nz.

Regional support groups also give information and support to Coeliacs and their families/ caregivers. The Wellington Support Group provides coverage from Waikanae and Upper Hutt south. Coordinator is Bill Darnell – contact at 04 232 4852 or email darnell@paradise.net.nz

Further Information for Health Workers

The Coeliac Society website as noted above is available and the Society has staff who are always available to provide advice. Membership of CNZ is available and magazines and published materials will help give a better understanding of the condition and how to assist patients.

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Coeliac NZ Membership Coverage

| | Population | Population | 1 in 70 | 20% | CNZ | Percent of | |
|--------------------------|------------|------------|---------|-----------|------------|------------|--|
| | 2013 | 2017 Est | Coeliac | Diagnosed | Membership | diagnosed | |
| Whangarei | | 80,000 | 1143 | 229 | 52 | 23 | |
| Northland | | 85,000 | 1214 | 243 | 26 | 11 | |
| Warkworth | | 40,000 | 571 | 114 | 37 | 32 | |
| Hibiscus Coast | | 65,000 | 929 | 186 | 46 | 25 | |
| Auckland North | | 600,000 | 8571 | 1714 | 208 | 12 | |
| Auckland Central | | 800,000 | 11429 | 2286 | 119 | | |
| Coromandel | | 28,000 . | 400 | 80 | 7 | 5 | |
| Te Aroha/Paeroa/Thames | | 45,000 | 643 | 129 | 37 | 29 | |
| Tauranga | | 160,000 | 2286 | 457 | 140 | 31 | |
| Rotorua | | 65,000 | 929 | 186 | 45 | 24 | |
| Taupo | | 34,000 | 486 | 97 | 21 | 22 | |
| Waikato | | 86,000 | 1229 | 246 | 227 | 92 | |
| Gisborne Wairoa | 51,000 | 58,000 | .829 | 166 | | | |
| Hawkes Bay | 151,000 | 175,000 | 2500 | 500 | 77 | 15 | |
| Taranaki | 100,000 | 120,000 | 1714 | 343 | 49 | 14 | |
| Wanganui | 51,000 | 55,000 | 786 | 157 | 24 | 15 | |
| Wairarapa | 45,000 | 53,000 | 757 | 151 | 35 | 23 | |
| Wellington | 422,000 | 470,000 | 6714 | 1343 | 359 | 27 | |
| Nelson | 93,000 | 100,000 | 1429 | 286 | 74 | 26 | |
| Marlborough | 43,000 | 47,000 | 671 | 134 | | | |
| West Coast | 31,000 | 33,000 | 471 | 94 | 10 | 11 | |
| Palmerston North | 150,000 | 170,000 | 2429 | 486 | 94 | 19 | |
| Christchurch | 404,000 | 410,000 | 5857 | 1171 | 354 | 30 | |
| Ashburton | 56,000 | 65,000 | 929 | 186 | 29 | 16 | |
| Timaru (Stc Canterbury?) | 66,000 | 70,000 | 1000 | 200 | 56 | 28 | |
| Southland | 94,000 | 95,000 | 1357 | 271 | 83 | 31 | |
| Queenstown/C Otago | 46,000 | 50,000 | 714 | 143 | 27 | 19 | |
| Dunedin | 125,000 | 140,000 | 2000 | 400 | 125 | 31 | |