Crohn's & Colitis Australia

CCA pre-training reading

CCA
7-4-2024

Australia

Welcome

to pre-training reading!

Before we meet and go through the most important aspects of becoming a successful support volunteer it is essential that you familiarise yourself with Crohn's & Colitis Australia (CCA), Inflammatory Bowel Disease (IBD), the Impacts of IBD, and the help line services provided by CCA.

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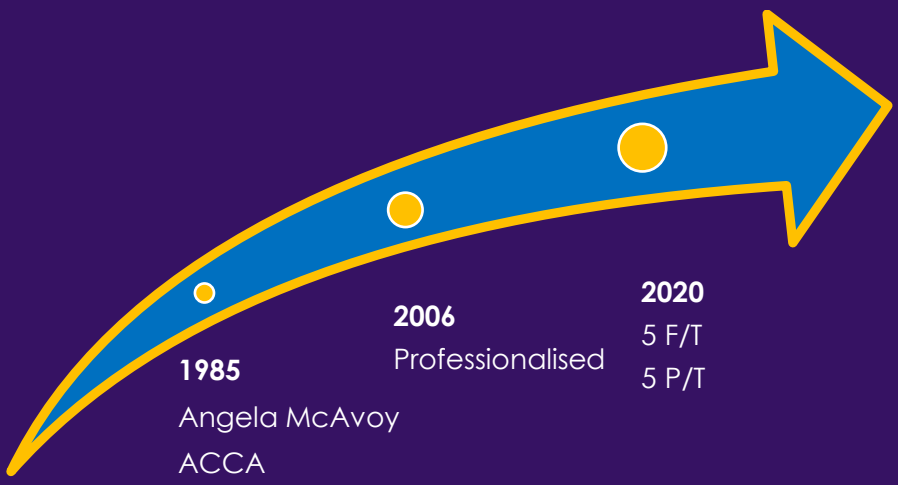


Angela McAvoy AM

Crohn's & Colitis Australia (CCA) is the peak body representing more than 85,000 Australians living with inflammatory bowel disease (IBD). CCA was founded by Angela McAvoy AM (Australian Crohn's & Colitis Association), after she was diagnosed with Crohn's disease and discovered there was no support service available in Australia. Angela led the organisation as a volunteer for 21 years before the first CEO was employed in 2006. Initially, CCA was run by volunteers. At present CCA have 5 full-time and 5 part-time staff. CCA does not receive State or Federal Government funding. CCA rely on the generosity of volunteers, donors, and community fundraising to continue its mission.

What does CCA do?

As part of CCA's mission we conduct various projects aimed at improving outcomes for people living with Inflammatory Bowel Disease (IBD), for example Australian IBD Standards 2016, IBD Audit, IBD National Action Plan and Patient Experience Survey. Our members have access to exclusive benefits such as:

The official magazine of Crohn's & Colitis Australia features news from CCA, stories on the latest research in IBD, personal stories from the Crohn's and colitis community, tips on lifestyle strategy and plenty more

This comprehensive information page is an extensive resource including information on more than 20 different topics that can directly affect people living with Crohn's or ulcerative colitis. There are contributions from medical experts, and it includes detailed information regarding diet and nutrition, medications, surgery, emotional factors, children and IBD, etc.

A fortnightly digest on news from CCA, featuring invitations to upcoming forums, youth programs, and other events, updates from the Crohn's & Colitis Hub, research news and more, delivered straight to your inbox on every second Wednesday.

Can't Wait card to help members gain access to a toilet in times of urgency.

Also fundraising events, support programs such as Support Groups, Peer Connect, Helpline & Nurse-line and Forums, Youth Programs, Camps, and Ambassadors & Local Champions to assist with promoting CCA, and IBD awareness.

Australia

IBD
Crohn's Disease & ulcerative colitis

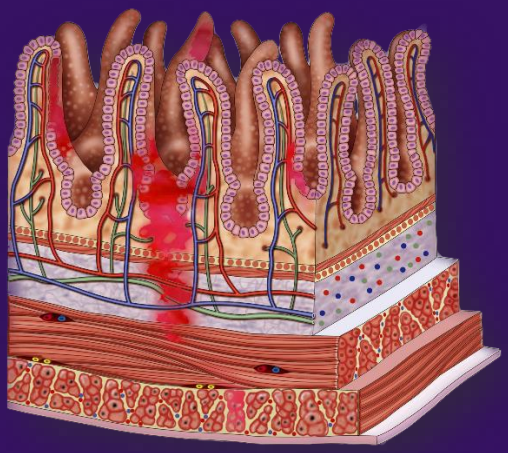
Crohn's disease

Crohn's disease can involve any part of the gastrointestinal tract from the mouth to the anus but most commonly affects the small intestine and/or the colon. There may be areas of healthy intestine between the areas of diseased intestine. Within a diseased section, Crohn's disease can affect all layers of the intestinal wall (i.e., not just the lining). This can lead to the development of complications that are specific to this condition:

- strictures (intestinal obstruction or narrowing of the intestinal wall),
- abscesses (boils) and skin tags (swollen lumps or 'flaps' of thickened skin occurring just outside the anus),
- fistulae (abnormal channels connecting different loops of the intestine to itself or to other body organs),

- fissures (ulcerated tears or cracks in the lining of the anal canal),

- Inflammation affects multiple layers of the bowel wall.



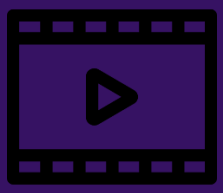
SURGERY In some cases, surgery may be required to correct the complications of Crohn's disease or to remove the diseased portions of the gastrointestinal tract (resection). Surgical resection is an important decision that needs to be taken in full consult with your clinical team as it is not a cure. Even if diseased parts of the intestines are removed, inflammation can re-appear in other areas.

SMOKING AND CROHN'S Smoking increases the need for surgery and medications, can make the disease more active and may prevent the induction of remission. After surgery for Crohn's disease, the condition may recur sooner, and often more severely in smokers than in non-smokers. If you have Crohn's disease and you smoke, it is important that you stop immediately.

DIET & NUTRITION Crohn's disease in the small intestine can impair the digestion and absorption of essential nutrients from food. During active stages of disease, many people try to avoid eating in order to prevent further symptoms. This worsens the tiredness and fatigue and eventually leads to weight loss. A well-

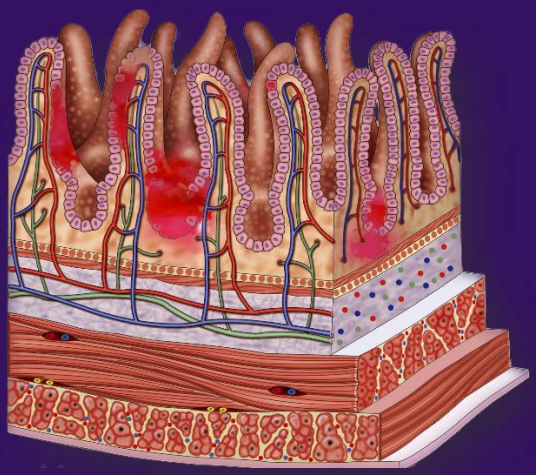
balanced and nutritious diet is essential for anyone with Crohn's disease in order to prevent malnutrition and maintain good health. And it is even more so for growing children and adolescents who may experience delayed growth or pubertal development in the absence of adequate nutrition.

Resources (Ctrl+Click):



Ulcerative colitis

In ulcerative colitis, inflammation occurs on the lining (mucosa) of the large intestine or colon. The inflammation is usually located in the rectum and lower colon but may involve other parts of the colon and sometimes even the entire colon. Tiny open sores or 'ulcers' form on the surface of the lining and these may bleed. The inflamed lining also produces a larger than normal amount of intestinal lubricant or mucus which sometimes contains pus. Inflammation in the colon reduces its ability to reabsorb fluid from the faeces which causes diarrhoea. Inflammation in the rectum can lead to a sense of urgency to have a bowel movement.



SURGERY In people with severe disease that is not responding adequately to medication or in those with long-standing disease (>10 years duration) who are at higher risk of colorectal cancer, surgical removal (resection) of the colon may be the most appropriate long-term solution.

Surgical resection eliminates the symptoms of ulcerative colitis and the need for ongoing use of medications to control inflammation. This can greatly enhance quality of life.

Surgery for ulcerative colitis generally involves removing the large intestine and creating a pouch from the end of the small intestine which is then joined directly to the anus. Alternatively, the end of the small intestine can be redirected to empty into a bag attached to an opening (stoma) on the outside of the abdomen.

DIET & NUTRITION Although there is no clinical evidence to suggest that specialist diets benefit persons with ulcerative colitis, good nutrition is essential to the healing process. When disease is active, many people lose their appetite or try to avoid eating in order to prevent further symptoms. Lack of adequate nutrition worsens the tiredness and fatigue and eventually leads to weight loss.

Children with ulcerative colitis may fail to develop or grow properly, particularly if they have long periods of active disease and/or receive frequent or prolonged treatment with high doses of corticosteroids.

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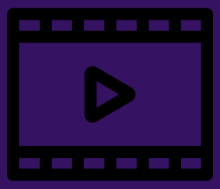
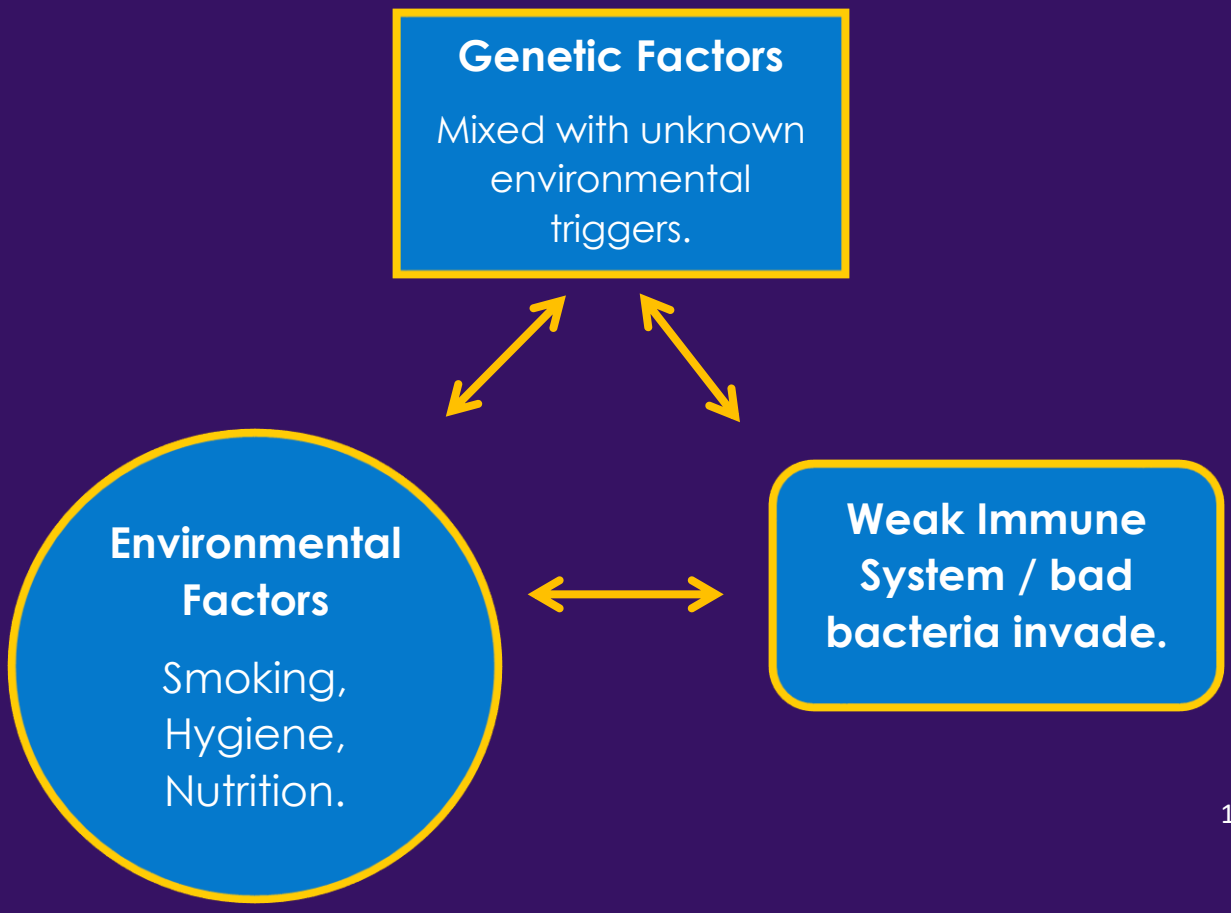


Possible Causes

No one knows for certain what causes IBD. At the moment, the best explanation that experts can provide is that several factors come together at the same time to set off the first episode of IBD. Firstly, there is likely to be a genetic susceptibility, where one or more genes a person has inherited makes them more prone to developing IBD. Should that person then encounter an environmental trigger – possibly, but not necessarily, a virus or bacterium or protein – the immune system is prompted to 'switch on', where it begins the very normal process of defending the body against a foreign substance. This process is known as inflammation, and it is here where things begin to go wrong. In most people, the immune response gradually winds down once the invading foreign substance has been destroyed. In some people, however, the immune system is unable to recognise or react to signals telling it to 'switch off' and the inflammation continues unchecked. This ongoing inflammation eventually causes damage to the intestinal tract and sets off the first episode of IBD.

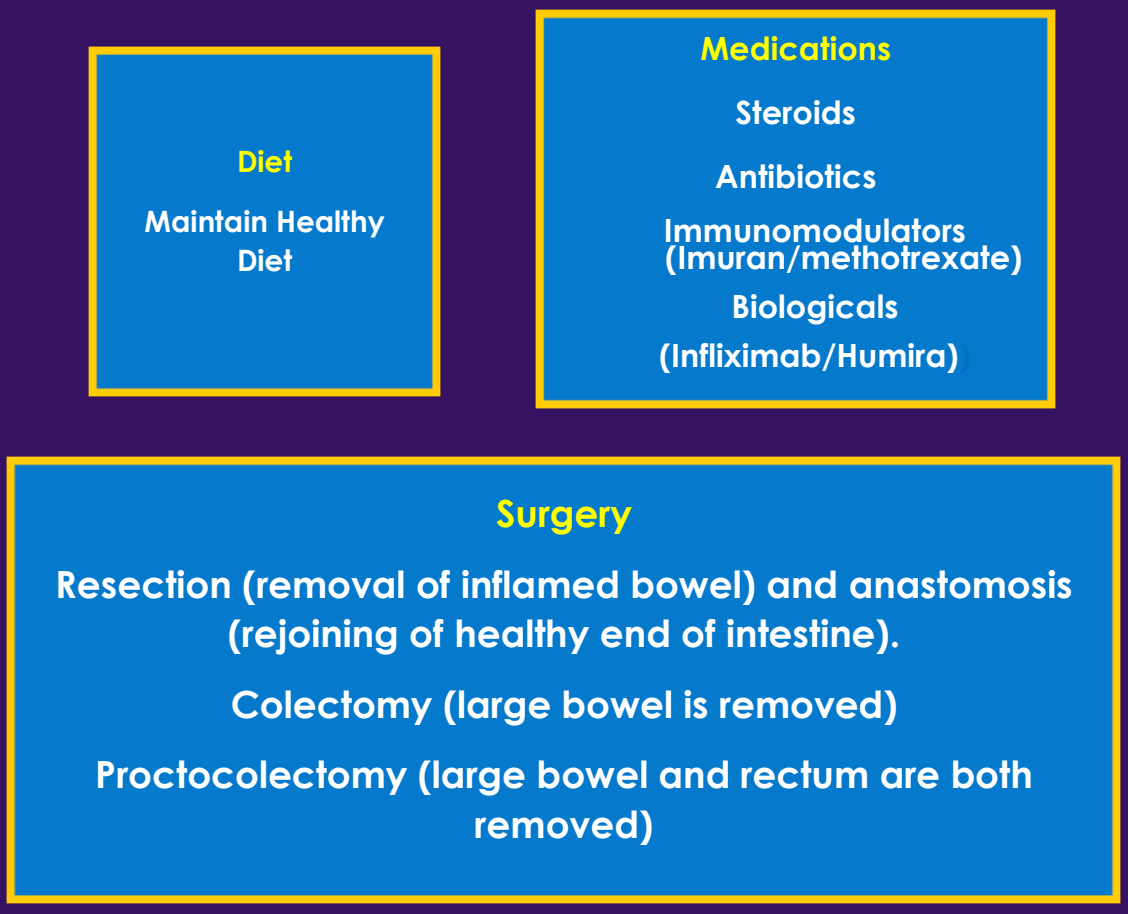


Environmental Factors: Smoking is a known risk factor for Crohn's. Hygiene hypothesis – modern lifestyle/being too clean; not exposed to a broad range of germs, then when in contact with organisms/infective agents it manifests into autoimmune & other conditions including IBD.

Diet/Nutrition – various theories – vitamin/mineral deficiencies, Western diets (no evidence).

Stress: Does not cause IBD but can exacerbate active IBD.

Managing Symptoms



Diet: Some dietary modifications may be necessary to help minimise symptoms. Usually temporary but may be required for

longer periods in people with Crohn's who have developed complications e.g., strictures (narrowing).

EEN – Exclusive Enteral Nutrition – used in paediatric cases on first presentation/diagnosis of IBD instead of using steroids.

Medications: Help dampen down inflammation or block specific pro-inflammatory chemicals (biologicals). Some medications taken continually for ongoing maintenance. Antibiotics assist with localised infection (complex Crohn's).

Other medications/binding agents (e.g., Questran) help in managing symptoms.

Surgery: Only performed when drug therapy has failed and when complications have developed. Resection/Anastomosis mainly Crohn's; Colectomy mainly u.colitis when rectal muscle required for fashioning ileal J-pouch; procto-colectomy performed in Crohn's & u.colitis requires a permanent stoma (ileostomy). There are other variations to these types of operations but depend on the individual situation. Fistula repair & treatment of abscesses in Crohn's also involves surgery. Strictureplasty (Crohn's) not common – does not involve removal, but rather a widening of the damaged, narrowed sections of gut.

There are many variables to IBD so there is no set treatment that works for everyone. Your own experience may be very different from others.

The impacts of IBD

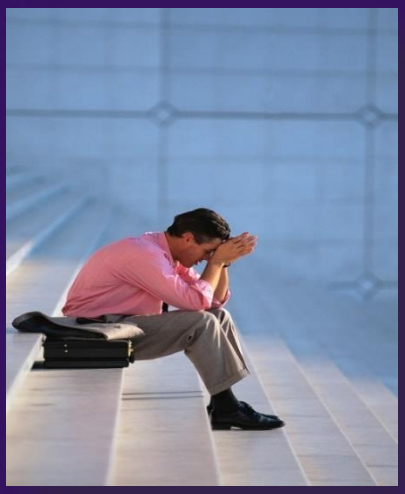
Emotional, Social and Lifestyle impacts of living with IBD

Stigma

Loss

Grief

Fear



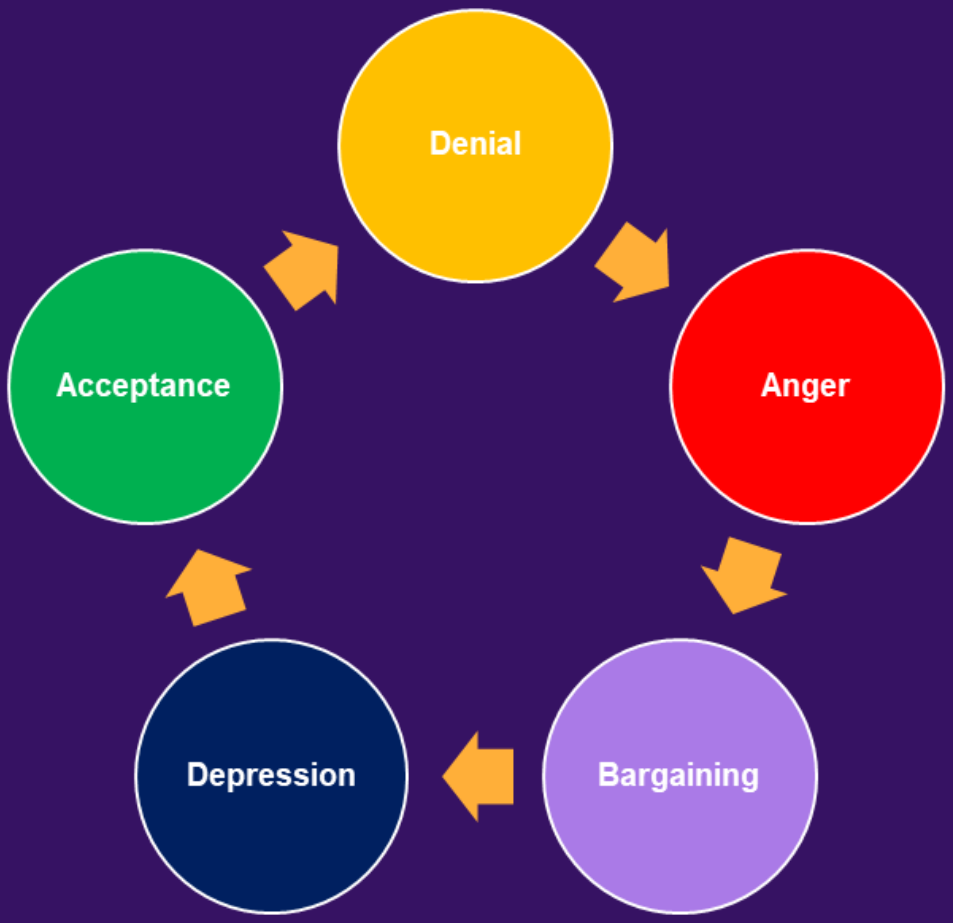
Stigma: is a perceived negative attribute. This can be expressed via verbal abuse, ignoring the person, questioning the authenticity of their illness, and negative judgments about lifestyle.

Loss: is the failure to preserve or maintain what one possessed – identity, control, independence, financial security, changes to lifestyle/future, relationships, physical abilities.

Grief: is a reaction to a significant loss. Grieving is the process of emotional and life adjustment gone through after a loss.

Fear: relates not just to fear about the disease or condition but involves all aspects of your life.

Stages of Grief



Five stages of grief: Shock & Denial, Anger, Depression & Detachment, Dialogue & Bargaining, and finally – Acceptance

The five-stage model of grief was developed by a Swiss psychiatrist Elizabeth Kübler-Ross in the 1960's. It was based on her experiences working with terminally ill people. It must be remembered, however, that even though the model presents five consecutive stages, grief is not a linear process. Therefore, some people may not go through all stages but rather through two or three instead. Nevertheless, for our purposes Kübler-Ross' model represents a useful platform for understanding and supporting people living with IBD.

Supporting someone who is grieving

Someone who is grieving needs

- Warm and open communication to make sense of what has happened
- Opportunities to come to understand the grief process
- Space to express their emotions
- Opportunities to have a break from their responsibilities
- Someone to check in with them
- Not to be judged
- Being listened to instead of being advised
- Not having their grief diminished
- No comprisons to your experience unless apropriate
- Others to avoid pushing their faith on them

Fear

1. Fear of loss of control

May fear loss of control over their life. Future plans are put into question. Uncertain day to day and whether they will ever regain control of their life.

2. Fear of changed self image

May no longer view self as the same person - less confident, feel unattractive, physically weaker, damaged, unable to earn a living.

3. Fear of dependency

Dependency and independence. Not wanting to show vulnerability. May have difficulty accepting outside help or giving into fears. May become overly needy and dependent.

4. Fear of stigma

Others may distance themselves. May withdraw into the confines of their home.

5. Fear of abandonment

Parental / relationship abandonment. Fear they will tire of the drudgery that the constant care involves. Disease threatening their personal sense of security.

6. Fear of expressing anger

When those suffering realize that they have done everything possible, yet can "never" be cured of their disease, they may become intensely angry. Anger is a consequence of frustration. Anger kept inside can cause depression and lack of energy.

7. Fear of isolation

Physical, social, and emotional isolation through physical confinement, lose the opportunity to socialize or withdraw. The fear of isolation usually doesn't occur immediately after their diagnosis. Can take time for this to occur.

8. Fear of death

Although everyone who is diagnosed with a serious chronic illness fears death, Irene Pollin says that, ironically, death is usually not what they fear the most. Rather, their greatest fears revolve around how they will live with the illness until they die.

Irene Pollin "Taking Charge: Overcoming the Challenges of Long-Term Illness."

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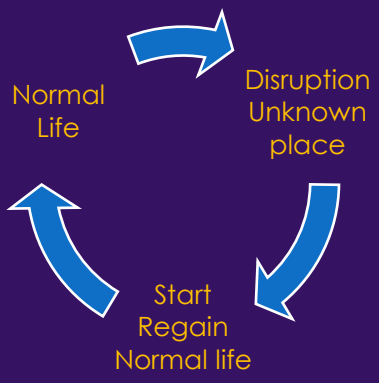
Transition



Normal life – predictable, knowing oneself

This comes to an end – being thrown into disruption/unknown place, all sorts of uncertainty

Remaining in a state of uncertainty – experiencing loss, grief, confusion

Reclaiming normality – ability to manage self, becoming normal again, progressing, healing

Being patient

Taking action to reshape the future, e.g., attending a meeting (first step)

What is important right now

What is achievable

Thinking about change doesn't create change – action does

Thinking about desired outcomes

Trying to reclaim aspects of who we were in the past and who we are now

Adapting through trial and error

Taking own actions on issues

Starting to attend Support Group or going for a walk

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What is Diversity?

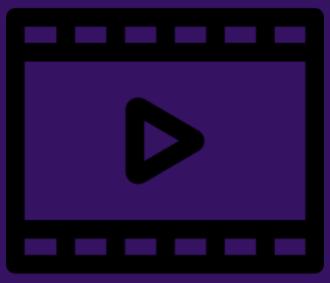
- Recognizing and appreciating the characteristics that make us different.
- Everyone deserves dignity and respect.
- All have different experiences and ideas.

Characteristics:

- Age
- Culture/ethnicity/language
- Disability
- Economic background
- Education
- Gender identity
- Geographic background
- Marital / partnered status
- Physical appearance
- Political affiliation
- Race
- Religious beliefs
- Sexual orientation

Stereotypes

- Can be a barrier to good communication.
- Need to accept people as individuals.
- Need to recognise stereotypes for who they are.
- Not all individuals fit the stereotype.



Emotions and reactions to chronic illness

The impact of chronic illness on a person's life is usually quite significant, affecting multiple life areas. First, there is chronic illness itself with its unpredictability, functional difficulties and even disability. People often feel angry, depressed, and frustrated by repeated flare-ups of disease which require prolonged rest and/or hospitalisation and interfere with their social activities. Furthermore, illness and the treatment influence person's appearance and consequently self-image and self-confidence. Chronic illness may have an impact on relationships, sexuality, fertility, and other members of the family. Finally, education, work and therefore the finances can also be affected. It is not surprising that a person affected by such a complex and debilitating disease may experience a wide spectrum of emotions such as: alienation, anger, appreciation, confidence, depression, despair, determination, denial, disbelief, frustration, guilt, helplessness, hope, huge learning curve, isolation, loneliness, loss (general), loss of control, love, pain, questioning, reassessment, regret, relief, sadness, self-pity, self-reliance, self-respect, shock, strength, support, vulnerability, weaknesses. But also, if supported, a person may develop acceptance and a positive attitude towards challenges. Support groups may facilitate that!

Thank you!