

INFORMATION SHEET

GRIEF AND LOSS

26 July 2022



ENDOMETRIOSIS AT A GLANCE

Endometriosis is a condition where tissue similar to the endometrium (the lining of the uterus) grows elsewhere in the body. This tissue responds to reproductive hormones where oestrogen stimulates patches forming superficial, lesions or endometrioma (ovarian cysts). Inflammation is generally present, and adhesions (scar tissue) can also form in response. Endometriosis within the muscle tissue of the uterus is known as adenomyosis, typically characterised by an enlarged uterus and heavy menstrual flow as well as pain at time of period.

The thoughts, feelings, and reactions we experience when faced with change and loss, are known as grief. Grieving is a very individual process.

For those with endometriosis and other chronic illnesses, changes in health and lifestyle can cause a feeling of grief and loss. The type of grief that comes with chronic illness is complex, and there is no 'right way' of grieving.

Chronic illness can impact a person's mobility as well as the ability to keep up usual everyday routines, to do familiar tasks, or be in usual roles. The ability to drive may be lost as well as opportunities to do things anticipated or planned such as study and travel. Your symptoms may impact your employment, income, and career plans, as well as your ability to socialise with friends and family and impact your relationships.

Grief and a sense of loss can start at diagnosis or earlier. With daily reminders and frustrations about what's been lost, or with new health issues arising or crises happening, you may feel you are in a continuous cycle of loss and grief.

SIGNS OF GRIEF

While grief about health affects people in different ways, common feelings of loss include a person feeling that they have lost:

- their old self – how they used to be (identity)
- their sense of control over their body or mind
- independence
- confidence – in themselves, in the future
- self esteem
- privacy and dignity
- life as it was
- their sense of place in the world

Many factors will play a part including your personality, your life experiences, your ability to cope under stress, and also learned coping strategies.

WHAT CAN HELP?

Grief can affect us emotionally, physically, mentally, socially, and spiritually. Grief is a difficult thing to live with and live through and any kind of loss needs acknowledging and grieving for, whatever it is. Make time to grieve honestly for what has changed and been lost. It may help to think of grief as a process that helps to adjust gradually to what's happened.

Below are some tips to manage chronic illness grief:

- allow yourself to feel and express your feelings; learn how to have those difficult conversations
- educate yourself as much as possible about your condition and take an active role in your treatment. This may help regain a sense of control and improve your self-esteem
- be realistic about what to expect from yourself
- let go of expectations, do what you need to do for yourself and understand that other people and society's definition of what's normal doesn't apply
- establish a good relationship with a supportive health care provider
- join a support group,; talking to people that have similar experiences and feelings can help
- communicate with friends, family, and your partner
- learn to adapt, make substitutions and modifications so that you can still participate in life activities
- listen to your body, pamper, and nurture yourself through eating well, gentle exercise, and prioritising quality sleep and rest
- make peace with your chronic illness
- practice self-care and self-compassion (we have a fact sheet on this topic)

Sometimes grief can go unrecognised or unacknowledged by others, who don't realise the *huge* impact that a change in health can have. Talking assertively to those around you is important so they have a clear understanding of how your health is impacting you; this will enable them to have compassion for what you are experiencing and provide the support and practical help you need (see our 'Talking About Your Endometriosis With Your Family and Friends information sheet')

ENDOMETRIOSIS AND COPING WITH FERTILITY DIFFICULTIES

Problems conceiving may involve a series of losses - loss of hopes and dreams, loss of control, loss of a positive self-image, loss of privacy, loss of feeling connected, belonging and many more. These losses may be invisible to others. Those experiencing fertility problems may feel lonely and isolated from friends and family, and sometimes from their partner. With uncertain outcomes, coping with fertility treatments can compound these issues.

Some social gatherings might be hard to cope with. While some conversations may be difficult or painful, with some preparation they may also be an opportunity to explain your situation to friends and seek support. Aim to open and assertive rather defensive. And remember that just because a question is asked does not mean you have to answer it.

Below are some coping strategies if you are experiencing infertility:

- seek information from fertility specialists, counsellors or Fertility NZ and inform yourself about the options available to you
- join a local support group: sharing experiences can be helpful and help you to feel less isolated
- look after yourself: self-care can help minimise the negative impact that fertility problems can have on your mind, body and soul
- research shows that writing or drawing about painful experiences is therapeutic and can be a form of release during tense and stressful times.

SEEKING HELP

Some people start to feel better in weeks or months, while for others it may take much longer. Whatever your grief experiences, it is important to be patient with yourself, take time to grieve, and seek help if you sense the need.

It's especially important that you talk to your doctor or a counsellor if you:

- feel disconnected
- are unable to perform your normal daily activities over an extended period
- feel life isn't worth living
- are having difficulty trusting others since your loss.

HELPLINES

- 1737, Need to talk? Free call or text 1737 to talk to a trained counsellor
- Depression.org.nz 0800 111 757 or text 4202
- Lifeline 0800 543 354
- Mental Health Foundation 09 623 4812, to access its free resource and information service
- Rural Support Trust 0800 787 254
- Samaritans 0800 726 666
- Suicide Crisis Helpline 0508 828 865 (0508 TAUTOKO)
- Fertility NZ 0800 333 306

For further information:

- Insight Endometriosis: Talking about your endometriosis with your partner
- Insight Endometriosis: Talking about your endometriosis with family and friends
- Insight Endometriosis: Mental Wellbeing and Self-Care
- Insight Endometriosis – Endometriosis, Depression and Anxiety

References:

- Skylight – www.skylight.org.nz
- Grief Support Services – www.griefsupport.org.nz
- Fertility NZ – www.fertilitynz.org.nz

Visit: www.insightendometriosis.org.nz

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