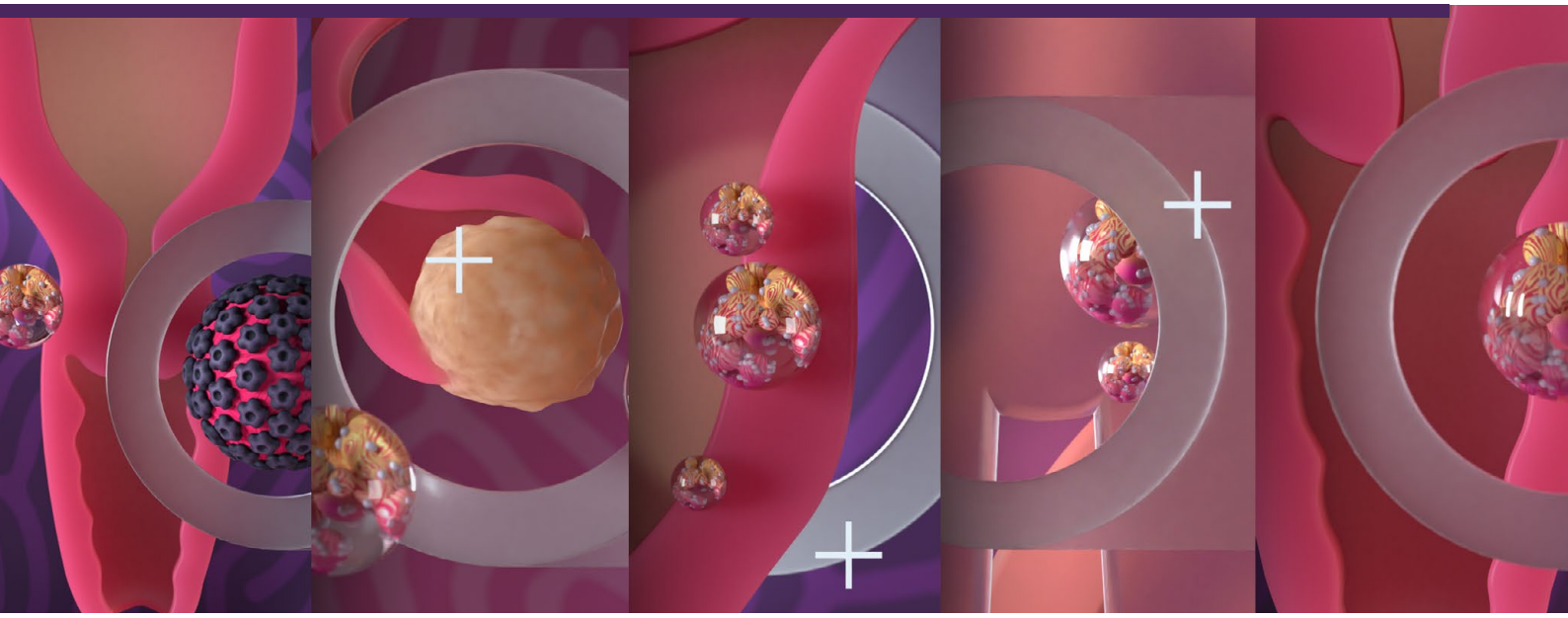

Gynaecological cancers – follow-up and surveillance

Follow-up and surveillance of patients who have undergone curative-intent treatment for gynaecological cancer is an opportunity to identify recurrence as early as possible, and therefore optimise outcomes. Most cases of recurrence occur within two to three years post-treatment and patients are generally symptomatic; patients must be encouraged to seek advice if symptoms occur between scheduled follow-up appointments.

This article follows on from the early detection and referral series of articles on **cervical**, **ovarian**, **endometrial**, **vulval** and **vaginal** cancers

KEY PRACTICE POINTS

- The risk of gynaecological cancer recurrence is linked to the type of tumour and stage of the disease at diagnosis, and also depends on the treatment received, characteristics of the primary tumour, including lymph node involvement and any additional risk factors, e.g. increasing age
- In the majority of cases, gynaecological cancer recurs locally in the pelvic region within the first two to three years following primary treatment
  - If identified early, local recurrence of gynaecological cancers are treatable and potentially curable
- Most patients with gynaecological cancer recurrence are symptomatic. Symptoms and signs may include abnormal vaginal bleeding, a vulval or vaginal lesion or mass, abdominal or pelvic pain, abdominal distention or bloating, urinary symptoms, weight loss.
  - Advise patients to return to primary care for examination if symptoms or signs of recurrence arise in between follow-up appointments; emphasise that they should not wait until their next planned appointment
- After a patient has completed treatment for cancer, primary care providers should ideally receive a copy of the patient's management summary and follow-up treatment plan from the treating specialist. Ensure that it is clear who will be responsible for aspects of the patient's ongoing follow-up and what this will entail.
- The frequency and duration of follow-up after gynaecological cancer is largely determined by the cancer type and stage at diagnosis. Follow-up is typically more frequent during the first two to three years post-treatment.
  - The New Zealand Gynaecological Cancer Group has developed national guidelines for cervical and endometrial cancer follow-up, stratified by risk
- The main components of follow-up are a focused patient history to identify any relevant symptoms of recurrence and a physical examination, including speculum and bimanual vaginal examination, and rectovaginal examination if indicated
  - Imaging and laboratory tests are not usually required unless there is clinical suspicion of recurrence
  - Other important aspects of follow-up include the monitoring and management of any treatment-related adverse effects, regular assessment of the patient's mental health and wellbeing and promotion of healthy lifestyle factors
- Consider the physical (taha tinana), psychological (taha hinengaro), social (taha whānau) and spiritual (taha wairua) needs of the patient and their family/whānau throughout follow-up and surveillance appointments; refer to the Cancer Society NZ or other organisations for support

N.B. The term "female" is used in this article to describe the biological sex of the patient population who have undergone curative-intent treatment for gynaecological cancer. However, we acknowledge that this may not reflect the identity of all patients, which will include transgender boys or men, intersex and non-binary individuals.

Follow-up is an opportunity to identify recurrence as early as possible

Follow-up and surveillance is an opportunity to improve outcomes for patients who have undergone curative-intent treatment* for gynaecological cancer. It aims to detect any recurrence early, so that potentially curative treatment can be offered (if required) or for early control of symptoms.[1,2] However, early detection of recurrence does not always improve survival. A number of different healthcare professionals may be involved in providing post-treatment care.[1]

* Curative-intent treatments include surgery, chemotherapy and radiation

The main goals of post-treatment care are to:[1,3,4]

Detect potential recurrence or new cancer to enable timely and appropriate management

Prevent, identify and manage any late/chronic physical or psychosocial effects of cancer and cancer treatment

Deliver ongoing education and support to facilitate the patient gaining greater independence and self-management of their ongoing health and wellbeing

Primary care is well placed to provide post-treatment care

There is variable provision of cancer post-treatment care across the country with many potential contributing factors, including:

- **Patient/whānau:** co-morbidities, priorities and preferences, geographical and social isolation
- **Clinical pathway:** expected or unexpected health complications
- **Cancer:** histology, stage and prognosis, effectiveness of adjuvant and second-line interventions and surveillance
- **Access:** availability of resources or services
- **Co-ordination:** strength of links between tertiary, secondary and primary health care services and community support services

While follow-up of patients treated for gynaecological cancer has traditionally taken place in secondary care, this can be provided in the community in many instances, e.g. by a general practitioner or nurse practitioner, or via outpatient services with a clinical nurse specialist.

Community-led follow-up encompasses the patient's cancer-related care, as well as management of co-morbidities and other health and wellbeing needs. Primary care clinicians are well-placed to provide tailored care as they are usually more familiar with the patient's medical and social history and health needs.

Potential issues with community-led follow-up include the time constraints on general practice and additional cost to patients of primary care appointments, which can be a significant barrier to access.

Symptoms and signs of gynaecological cancer recurrence

The risk of gynaecological cancer recurrence is linked to the type of tumour and stage of the disease at diagnosis, and also depends on the treatment received, characteristics of the primary tumour, including lymph node involvement and any additional risk factors, e.g. increasing age.[1,5,6] Time to recurrence is unpredictable, but most recurrences occur within two to three years of the primary treatment.[1,3,7]

Estimates of recurrence rates for individual gynaecological cancers vary across the literature and data are not available in New Zealand. International sources report the following:

- **Endometrial.** Most people treated for early endometrial cancer have a low risk of recurrence; recurrence rates range from 2 – 15% for early stage disease and reach up to 50% in advanced stage endometrial cancer.[1,8] People with Type II endometrial cancers (i.e. non-oestrogen dependent) typically have a higher rate of recurrence than Type I (approximately 50% and 20% respectively).[9] Many local recurrences are curable.[1]
- **Ovarian.** Ovarian cancer recurrence rates are high and are rarely curable; recurrence occurs in approximately 25% of people with early-stage ovarian cancer and in more than 80% of those with advanced stage disease.[1,3]
- **Cervical.** Recurrence rates for stage I cervical cancer, which account for approximately 90% of all diagnoses, can be as high as 10 – 20%, but local recurrences are often curable.[3] Although less common than squamous cell carcinoma, the risk of recurrence is greater in people with adenocarcinoma of the cervix.[10]
- **Vulval.** Recurrence rates vary widely depending on the type of vulval cancer (e.g. HPV-independent vulval squamous cell carcinoma and melanoma have a high risk of recurrence and poor prognosis), lymph node involvement and duration of follow-up.[1,7,11,12] Overall recurrence rates have been reported between 12 – 37% in people with primary squamous cell carcinoma of the vulva.[13] N.B. HPV-independent squamous cell vulval cancers tend to recur later than two to three years post-treatment; primary care clinicians are likely to have a role in the long-term monitoring for recurrence.
- **Vaginal.** Reported recurrence rates vary from 24% for stage I, 31 – 32% for stage II, 53% for stage III and up to 83% for stage IV.[5]

Most recurrences occur locally in the pelvis as opposed to distant sites.[1, 7, 14] The majority of people with gynaecological cancer recurrence are symptomatic (Table 1).[2, 15] Asymptomatic recurrence may be detected from abnormal findings from a physical examination, e.g. mass, lesion.[1, 3] Symptom review and physical examination are therefore the most common methods to detect gynaecological cancer recurrence (see: "Follow-up and surveillance recommendations").[1, 3, 16]

Table 1. Typical symptoms and signs associated with gynaecological cancer recurrence.[1, 3]

Local	■ Abnormal vaginal bleeding or discharge ■ Pelvic or genital lesion or nodule/mass ■ Pruritus in the genital area
Distant	■ Abdominal or pelvic pain ■ Abdominal bloating or distention ■ Leg or groin pain ■ Lymphoedema ■ Changes in urinary or bowel habits ■ Lethargy ■ Weight loss ■ Cough ■ Shortness of breath

Most recurrences are detected in patients with symptoms outside of scheduled follow-up appointments.[2] Advise patients to return for examination if any symptoms of recurrence arise in between follow-ups. Emphasise that they should not wait until their next planned appointment.

Follow-up and surveillance recommendations

On completion of cancer treatment, as part of survivorship care, the treating specialist will ideally share a copy of the patient's treatment summary (survivorship care plan) with their primary care provider, and this should be electronically accessible via a shared record storage system. A plain language summary should also be provided to the patient and their family/whānau. However, there is no consistent approach to this between regions and providers, therefore, the information that is received by the primary care team can, in some cases, be minimal. The key outcome is that there should be a clear plan established that sets out who will be responsible for the patient's ongoing follow-up cancer care and what this will entail.

The treatment summary should ideally include information on the:

- Diagnosis
- Treatments received and date/time of completion
- Long-term adverse effects that may occur and any laboratory monitoring or other investigations required
- Symptoms and signs that may indicate recurrence and need further investigation
- Follow-up plan that includes the providers involved (and contact details), the frequency and duration of follow-up (individualised, but typically two to five years) with a pathway for escalation if abnormalities are detected/reported
- Responsibility for follow-up, i.e. who will order investigations, review and act on results, provide treatment and monitor for adverse effects
- Documentation that the patient and their family/whānau understand the diagnosis and treatment, that prognosis has been discussed and **advance care planning** has been discussed or put in place (if appropriate)

The frequency of follow-up should be individualised

The New Zealand Gynaecological Cancer Group (NZGCG) has published recommended follow-up schedules for patients treated for endometrial and cervical cancers (see link below).[8] International guidelines provide recommendations for all gynaecological cancers.[1] However, there is not always a consistent approach to the follow-up of a patient post-treatment for gynaecological cancer in New Zealand, with some regions differing in which guidelines they follow, and approaches may vary according to clinical judgement.

The frequency and duration of follow-up is usually individualised based on the:[1, 2]

- Type of gynaecological cancer
- Treatment given
- Risk of recurrence
- Patient's co-morbidities

In general, patients are followed up for two to five years, with more frequent appointments during the first two to three years post-treatment as this is when the majority of recurrences occur.[1] Patients may be stratified into low, intermediate or high-risk groups based on the stage of disease at diagnosis, treatment type and any co-morbidities. Those at higher risk will typically be followed-up more often in secondary care during the first two to three years before being discharged to primary care, compared to those at lower risk of recurrence. Some people, e.g. those with HPV-independent squamous cell vulval cancer, can experience delayed recurrence and may require long-term, i.e. life-long, surveillance.[3, 7, 17]

Deciding when to stop regular follow-up should be a shared decision between the patient and clinician(s) and occur if it is thought that the risks of further investigation outweigh the likely benefits, when the patient can no longer tolerate

further treatment or when no further active treatment is available and supportive care is more appropriate.

Best Practice Tip. If a patient is receiving follow-up in secondary care, place a recall to check with the patient that these appointments have occurred (the recall can be cancelled if a follow-up letter is received).

NZGCG follow-up recommendations for endometrial and cervical cancer are available from: **www.health.govt.nz/system/files/documents/publications/2015_nzgcg_follow_up_recommendations_0.pdf**

A focused patient history and physical examination are the most common methods of gynaecological cancer recurrence detection

It is not intended that all aspects of follow-up after treatment for gynaecological cancer are covered in the same appointment. These checks may take place in dedicated follow-up appointments, opportunistically during appointments for other reasons and over time.

For all gynaecological cancers, follow-up generally consists of a **focused patient history** to identify any relevant symptoms of recurrence (Table 1) and a **physical examination**.[1–3, 16] The physical examination should include palpation of relevant lymph nodes and an abdominal and pelvic examination including a speculum examination (looking for any local signs of a lesion, nodule, mass, ulceration or bleeding), bimanual and rectovaginal examination (feeling for any fullness or palpable mass).[1, 3, 9]

If abnormal findings are detected on examination or if there are symptoms of concern, urgently refer the patient to a gynaecologist. Also arrange appropriate investigations while awaiting the appointment, e.g. fine needle aspirate if nodes are palpable, pelvic ultrasound if suspected mass.

The use of cervical or vaginal cytology is not a reliable strategy for detecting recurrence of gynaecological cancers.[1, 3, 7, 14]

Participation in the National Cervical Screening Programme is no longer required for patients after a hysterectomy for gynaecological cancer unless there was a recent history of abnormal results prior to the hysterectomy. The patient's oncologist will provide guidance on whether cervical cytology (or vaginal vault cytology) is required after treatment for gynaecological cancer, including appropriate testing intervals. Cervical cytology is also not useful for patients after treatment with primary radiotherapy for gynaecological cancer, as these treatments can cause abnormal changes to cells (e.g. atypical squamous cells of undetermined significance) and lead to false positive results.[1, 2, 8] Further research is needed to determine the role that HPV testing has in gynaecological cancer follow-up.[1, 2]

Imaging and laboratory tests are not usually required unless there is clinical suspicion of recurrence.[1–3, 17] Serum CA 125 levels are often elevated two to five months prior to the clinical detection of ovarian cancer recurrence, however, routine testing is not required for surveillance as it has not been to shown to increase survival.[1, 3, 16]

Follow-up is also an opportunity to **monitor and manage any treatment-related adverse effects** (see: "Managing patients' needs following curative-intent treatment") and **assess the patient's mental health and wellbeing** (see: "Assess the patient's mental health and emotional wellbeing").

Managing patients' needs following curative-intent treatment

The nature, severity and duration of symptoms following gynaecological cancer treatment is influenced by various factors, including the type of treatment, the patient's general health status, co-morbidities, psychosocial and lifestyle factors. Patients should be educated about the potential symptoms of recurrence and how to manage any treatment-related adverse effects (see below). In addition, follow-up is an opportunity to assess general physical and psychosocial wellbeing and reinforce the importance of a healthy lifestyle, e.g. regular physical activity, balanced diet, weight management, smoking cessation, and ensure patients have access to support services.[1, 3]

Weight management is especially important in females after endometrial cancer as obesity is a strong risk factor for this cancer. There is some evidence that obesity at the time of an endometrial cancer diagnosis is associated with an increased risk of recurrence and all-cause mortality (but not endometrial cancer-specific mortality).[18] In patients who are overweight or obese, methods for weight loss, which may include consideration of bariatric surgery, should be offered as part of follow-up. Monitor for and optimally manage obesity-related conditions such as type 2 diabetes and cardiovascular disease.

For further information on weight loss, see: **bpac.org.nz/2022/weight-loss.aspx**

Monitor for any late or chronic effects of cancer and cancer treatment

The typical role of a general practitioner in monitoring for post-treatment effects of cancer is to identify the issue and then, if necessary, discuss management with the treating specialist,

depending on the patient's symptoms and situation, e.g. proximity to a hospital.

Late or chronic effects of cancer and cancer treatment that primary care may assist in managing include:

Fatigue

Most people experience some degree of fatigue during cancer treatment and approximately one-third of people experience persistent fatigue for many years.[3] Non-pharmacological approaches can be recommended, including exercise, cognitive behavioural therapy (if there is concomitant anxiety or poor coping skills) and mindfulness-based techniques, e.g. meditation, yoga.[3]

A free New Zealand-based cognitive behavioural therapy course is available for people with anxiety, for further information, see: **www.justathought.co.nz/anxiety**

Gastrointestinal-related effects

Altered bowel habits are commonly experienced by patients after radiotherapy.[6, 14] Gastrointestinal-related symptoms or complications may include faecal urgency, incontinence or leakage, diarrhoea or constipation, bleeding, malabsorption, ileus, obstruction and small intestinal bacterial overgrowth.[6, 14]

Depending on the severity of the patients symptoms and complications, it may be appropriate to recommend general lifestyle advice and dietary changes (e.g. increased fibre intake to relieve constipation) and to consider pharmacological treatments if required, e.g. loperamide for diarrhoea or laxatives for constipation.[4, 7, 14] Refer patients with severe symptoms or complications, or persistent symptoms despite treatment, to an appropriate specialist for further assessment.

Urinary-related effects

Potential urinary complications following cancer treatment include increased urinary frequency, urgency or incontinence, pain, urinary retention, urethral stricture, obstruction, inflammation and detrusor instability.[6, 14]

Treatments may be offered to patients to manage some types of incontinence, or organise referral to a nurse specialist, physiotherapist or urologist depending on the specific complication.

For further information on urinary incontinence, see: **bpac.org.nz/bpj/2013/october/urinary-incontinence.aspx**

Menopausal symptoms

Following treatment for gynaecological cancer, some people experience premature menopause, and as a result have an increased risk of associated conditions such as osteoporosis and cardiovascular disease.[3, 19, 20] It can also significantly impact quality of life.[3]

Pharmacological treatment for menopausal symptoms e.g. vaginal oestrogen cream, systemic menopausal hormone therapy* should be discussed;[19, 20] it is often underutilised. Menopausal hormone therapy is usually suitable for patients who experience menopausal symptoms after treatment for most epithelial ovarian cancers, early stage endometrial cancer or cervical cancer.[19–21] It is not generally recommended for use in patients with advanced endometrial cancer, uterine sarcoma or endometrioid or low-grade serous ovarian cancer. Non-hormonal options include a vaginal moisturiser or lubricant.[4, 20]

N.B. Menopausal hormone therapy* may be considered for patients without a history of breast cancer who have had risk-reducing surgery that has induced menopause, e.g. people with Lynch syndrome or BRCA mutation.[19, 21] For further information about Lynch syndrome, see: **bpac.org.nz/2023/ovarian-cancer.aspx**

* Combined oestrogen and progesterone therapy should be prescribed to patients with an intact uterus

To optimise bone health, strength and resistance training exercises can be recommended, alongside advice about adequate intake of calcium and exposure to vitamin D.[20] Bisphosphonates may also be considered.[20]

For further information on menopausal hormone therapy, and bisphosphonates, see: **bpac.org.nz/2019/mht.aspx** and **bpac.org.nz/2019/bisphosphonates.aspx**

Sexual function

Sexual function is affected in up to 90% of people treated for gynaecological cancer and is most prevalent in those who have undergone hysterectomy or radiotherapy.[3, 14] Symptoms and signs may include genital numbness, vaginal shortening, fibrosis, stenosis or dryness and genital lymphoedema.[3, 4] Psychological factors related to the diagnosis and treatment of gynaecological cancer may also impair sexual function, e.g. anxiety, depression, embarrassment or body image issues, distress, pain, reduced libido.

Use of a vaginal dilator is often recommended for patients following radiotherapy to reduce the risk of vaginal stenosis.[4, 7, 14] For general vaginal dryness and discomfort, vaginal oestrogen cream can be prescribed, or recommend use of a vaginal moisturiser or lubricant during sexual intercourse.[4, 7, 14] Referral to a counsellor, ideally specialising in sex therapy, may be appropriate for patients experiencing significant strain on their relationships.

A pamphlet from the Cancer Society about sexuality and cancer is available from: **www.cancer.org.nz/assets/Booklet-sex-and-cancer-2.PDF**

Lymphoedema

Patients who have undergone surgery and/or radiation to the pelvic and inguinal lymph nodes are at risk for lower

limb lymphoedema.[3, 4, 7] If a patient reports new-onset leg swelling, consider requesting gynaecology assessment to investigate potential recurrence as the cause (indicate high suspicion of cancer on the referral) and request lymphoedema physiotherapy assessment.

Pelvic insufficiency fractures

Older people who are treated with pelvic radiotherapy have an increased risk of pelvic insufficiency fractures.[14] Strength and resistance training exercises may be recommended and the use of bisphosphonates considered in patients at higher risk, e.g. low BMI, baseline osteoporosis, post-menopausal.[22] Advise patients to return to primary care for examination if they experience any pelvic pain, pain on weight bearing or immobility.[14]

Peripheral neuropathy

Peripheral neuropathy, involving sensory, motor or autonomic symptoms, may be experienced by patients following chemotherapy; for some people, neuropathy could be permanent.[3, 14] If peripheral neuropathy is painful, consider appropriate pharmacological and non-pharmacological treatments.[3]

For information on managing neuropathic pain, and the use of gabapentinoids, see: **bpac.org.nz/bpj/2016/may/pain.aspx** and **bpac.org.nz/2021/gabapentinoids.aspx**

Changes in cognitive function

Cognitive changes, including short term memory loss and difficulty concentrating, can be experienced by some patients following cancer treatment, particularly with chemotherapy.[3] Older patients may be at an increased risk due to age-related cognitive decline.[23] The use of memory aids and reminders (e.g. using notes or an alarm) can be recommended, along with strategies such as doing cognitively demanding tasks when energy levels are highest.[3] Mindfulness-based techniques, e.g. meditation, yoga, and exercise may also be effective.[3]

Assess the patient's mental health and emotional wellbeing

In addition to physical symptoms, gynaecological cancer treatment can have a significant psychological impact on a patient; more than 85% of people treated for gynaecological cancer reportedly experience some degree of psychological distress.[3] This can lead to depression, anxiety, low self-esteem, fear, body image issues and social isolation.[6]

Patients or their family/whānau may be particularly anxious around the time of follow-up appointments, especially regarding recurrence.[2, 3] Be mindful of health care anxiety when interacting with patients post-treatment during appointments for any reason.

For Māori patients in particular, acknowledgement of a holistic philosophy/model can be important such as **Te Whare Tapa Whā** which encompasses physical (taha tinana), psychological (taha hinengaro), spiritual (taha wairua) and family/whānau wellbeing. Spiritual and cultural practices may help to address the psychosocial needs of a patient following the diagnosis and treatment for gynaecological cancer, e.g. some people find comfort in rituals, waiata or religious services.

Ask the patient if they are "ok"

At each appointment, ask the patient a general screening question about their mental health and wellbeing, e.g. are they bothered by feeling down, depressed or hopeless, having little interest or pleasure doing things, feeling nervous, anxious or on edge, not being able to stop worrying. If there are concerns, assess further and consider use of a validated patient tool, e.g. **Distress Thermometer**; a similar tool adapted for a New Zealand context is available **here**.

Refer the patient to support services such as the **Cancer Society** or other cultural support networks as indicated. Some districts offer a Cancer Psychological and Social Support Service (CPSSS) that is specifically aimed at providing support to patients and their whānau who traditionally find it more difficult to access and use such services. For further information, refer to your local HealthPathways.

For further information on screening tools for distress and depression, see: **bpac.org.nz/2019/ssri.aspx**

For information on pharmacological treatments for depression, see: **bpac.org.nz/2021/depression.aspx**

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