Condition Insight Report (CIR)

Cancer

Version 1.1

Released 03.06.20

Updated 27.03.23

PLEASE NOTE: This is a document for internal use only and not intended for distribution.

Throughout this document you will find links to external websites. These links are being provided as a convenience and for informational purposes only and do not imply on the part of Capita, IAS, DWP or DfC any endorsement or guarantee of any of the organisations, opinions or information (including the right to display such information) found on their respective websites. Any comments or enquiries regarding the linked websites or their content should be directed to the owners of the website.

Overview

What is the condition usually called / any abbreviations used?

Cancer

Brief overview of the condition

Cancer is a condition where cells in a specific part of the body grow and reproduce uncontrollably. The cancerous cells can invade and destroy surrounding healthy tissue, including organs.

In the UK, The 4 most common types of cancer are:

- Breast cancer
- Lung cancer
- Prostate cancer
- Bowel cancer

There are more than 200 different types of cancer, and each is diagnosed and treated in a particular way. You can find links on this page to information about other types of cancer.

What is the generally preferred term for someone with this condition?

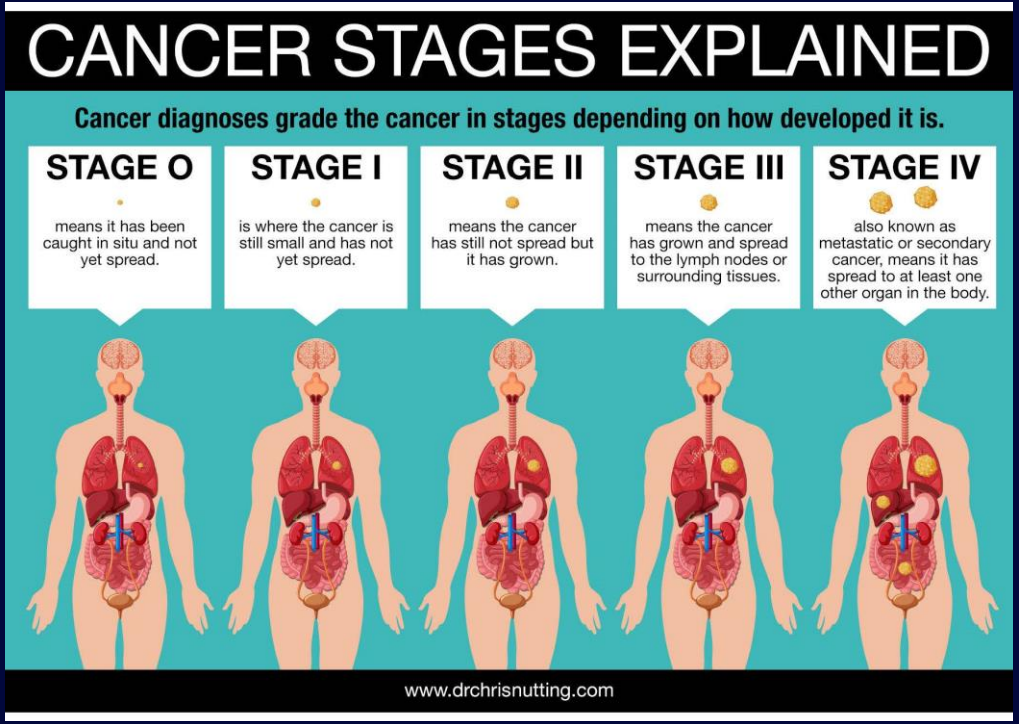
Living with cancer or a cancer survivor.

Presenting Symptoms

An individual can experience both physical and psychological symptoms from cancer treatment. Common symptoms can include, but are not limited to:

Physical symptoms/side effects:
- Nausea
- Fatigue
- Pain
- Hot flushes
- Pins and needles or numbness particularly in hands and feet
- Needing the toilet more frequently or incontinence, diarrhoea and colitis
- Impaired cognitive function

Psychological symptoms:
- Feeling on edge
- Having a sense of dread particularly of any physical symptom in case it is a recurrence of the cancer
- Feeling restless and finding it difficult to concentrate
- A sense of sadness and loss that can lead to depression



CANCER STAGES EXPLAINED

Cancer diagnoses grade the cancer in stages depending on how developed it is.

STAGE O means it has been caught in situ and not yet spread.

STAGE I is where the cancer is still small and has not yet spread.

STAGE II means the cancer has still not spread but it has grown.

STAGE III means the cancer has grown and spread to the lymph nodes or surrounding tissues.

STAGE IV also known as metastatic or secondary cancer, means it has spread to at least one other organ in the body.

www.drchrisnutting.com

Treatment and Side effects

There are several different treatment modalities and people may have a combination of treatments. All can have differing long-term effects. These consist of:

- **Surgery**
- **Chemotherapy**
- **Radiotherapy**
- **Targeted therapies/Immunotherapy**

When on treatment, people can experience side effects that cause nausea, vomiting, fatigue, diarrhoea, change in body image, skin problems, cognitive and functional problems and low mood. People experience these differently depending on the treatment.

It is imperative to remember that some people will suffer with therapy related symptoms for up to 12 months after the treatment has finished.

Surgery is the primary treatment for most solid cancer types (lung / colorectal etc.), especially if they are contained in one area of the body. However, sometimes people will have chemotherapy and or radiotherapy prior to surgery – this is called Neoadjuvant treatment often to eradicate lymph nodes or shrink a large tumour to ensure complete removal during surgery. They may also have chemo/radiotherapy after surgery to mop up any stray cancer cells and prevent recurrence – this is called adjuvant treatment. If people have more than just surgery, treatment can be protracted and take 9–12 months then a period of recovery is required, sometimes 6-12 months before back to normal. Sometimes people don't return to normal and must learn to live with a "new normal".

Side effects can include diarrhoea, adhesions, lymphoedema, fatigue, fertility issues, nerve problems, mouth and throat problems, pain, sexual health issues, sleep problems, urinary and bowel problems, mental health conditions such as depression or distorted self image.

Chemotherapy can be used before other treatments (usually stage 3 or 4 cancers to target lymph nodes before surgery), as a primary treatment, secondary or adjuvant treatment to reduce risk of recurrence by destroying any cancer cells that may remain after surgery or radiotherapy. It can also be used to slow down the growth of an incurable cancer or to ease symptoms.

Chemotherapy is used to treat many types of cancer but unfortunately will kill healthy cells as well as cancerous cells.

Symptoms/side effects of chemotherapy treatment – Fatigue, hair loss, bruising easily, infection, anaemia, nausea and vomiting, mouth sores, poor appetite and constipation or diarrhoea are the most common side effects of treatment.

Long term effects that may impact on daily life include fatigue, impaired cognition (chemo brain and difficulty concentrating), early menopause, heart problems, reduced lung capacity, kidney and urinary problems, neuropathy particularly in hands and feet, muscle weakness, secondary cancers and bone and joint problems.

Symptoms/side effects of targeted therapies – Skin problems, high blood pressure, clotting problems, gastrointestinal perforation, flu like symptoms, shortness of breath, leg oedema, diarrhoea, hormone changes and endocrine problems.

Some effects of immunotherapy can be life changing (person has to live with long term) and life limiting if not diagnosed early (severe colitis and pneumonitis).

Radiotherapy uses ionising radiation generally as part of cancer treatment to control or kill cancer cells. There are different types of radiotherapy.

Radiotherapy can be given as part of cancer treatment (before or after surgery or in combination with chemotherapy) or as the main treatment. It relies on imaging tests to map out treatment. External radiation is given from outside the body and beams deliver treatment from multiple angles to destroy cancer cells. Internal radiotherapy is when radioactive material is placed inside the body – it is sometimes called brachytherapy or radioisotope therapy. In some types of radiotherapy people must be immobilised so they cannot move during treatment.

Side effects include: Tiredness, problems eating and drinking, skin reactions, nausea, diarrhoea, heart problems if radiotherapy to chest, lymphoedema if radiotherapy that includes axillary or femoral areas, bladder and bowel or sexual function changes with pelvic radiotherapy, cataracts, decrease in range of motion in treated area and memory problems impacting ability to learn.

Where children have had whole body radiation they can have lots of long term effects as all organs are affected – heart, endocrine, long term fatigue, blood clots causing stroke in early adult life, diabetes, hearing and sight problems.

Fluctuations

Think about exploring things like:

- If undergoing treatment such as chemotherapy or radiotherapy, when did this start? How many cycles are they expected to go through? How many times a week will the treatment be required?
- Have there been any instances where they are not able to go through treatment due to poor health or tolerance?
- How do they feel throughout the cycle? What are they like the day of treatment? The following day and subsequent days following?
- Does function vary throughout different times of the cycle?
- Is the claimant expected to undergo radiotherapy or surgery following chemotherapy? If so, are there any plans for this?
- Has the cancer diagnosis had an impact on the claimant's mental health? If so, how does this manifest and impact on function?

Where pain/fatigue are reported:

- **What level?**
  Can they quantify this, do they use a scale and can they describe it? What level of severity? Can they share what a 'typical' day might be for them?
- **Triggers?**
  Whilst exertion is a main trigger what amount of exertion is enough to cause further limitation?
  How are triggers managed?

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY

Do they have any symptoms which could cause a safety consideration?

It is important to explore safety for both physical and/or their cognitive changes. E.g. altered sensation may affect grip and safety in the kitchen if an individual is fatigued and does not concentrate on chopping items. Poor balance and fatigue may cause safety restrictions in the bathroom.

TIMELY

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

Pain, fatigue, and other symptoms can all affect time frames of how long it takes an individual to complete a task.

Ensure to ask:

- How long it takes to complete tasks such as 1,4, 5, 6 and 12.
- Why they feel it takes them this long?
- Where they report having any breaks in task, how long are these breaks and how frequent?

ACCEPTABLE STANDARD

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

You need to consider whilst they might be able to physically use an aid, will it mitigate their symptoms sufficiently to make the task completion acceptable?

When asking the questions about their ability consider the types of aids which may be available for each activity, what is involved in using this and whether that is supportive for their restrictions or not.

REPEATEDLY

Are they able to repeat a task as often as required? Is this the same every day?

As fatigue can be a huge factor for those with cancer whilst they may be able to complete tasks this may not be the same every day. They may adapt by changing the timings of when they initiate tasks or need support to complete tasks at certain times. Establishing what covers the majority of days for them is important to supporting your advice.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

People with cancer have often had to struggle with the physical and psychosocial impact of their cancer, particularly if they are suffering long term effects of treatments or have incurable cancer that can be treated so they can live for several years, possibly on constant treatment.

Many find this difficult to admit or discuss that they may have suffered losses to their confidence, ability to work, physical and mental function and be low or frustrated. There may be incontinence and difficulty forming or maintaining certain relationships.

Watch this video about the **taboo topics** post cancer diagnosis **HERE**.

Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?

In general

- Brief them on exactly what the consultation involves and what they will be asked to do
- Listening, empathy and honesty when giving clear information, as well as allowing enough time without rushing is likely to be a good approach
- Ask them if they have any initial concerns about the consultation and see if you can address these
- Be prepared for what you would do if the consultation were to trigger any distress and the individual were to become extremely upset talking about the impact cancer has had on important areas of their life
- You could ask them if there are any adjustments that would make them feel more comfortable during the assessment e.g. ask if they would feel more comfortable if a friend or family member was be present with them
- Don’t just focus on their physical affects consider the emotional and psychological impact
- Offer them breaks if they need it

During face to face interactions

- Provide water if able, and tell them where the nearest toilets and exits are

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

The type of cancer will affect the impact of any pain, fatigue and other affecting symptoms. Some may struggle to stand for prolonged periods, have poor sensation and therefore control of dexterity and grip or have hypersensitivity and struggle to handle items and apply pressure. There may also be psychological impact causing apathy and poor motivation or cognitive impacts from medication or due to tumour site such as brain tumours.

Remember in PIP…

It is imperative to explore how someone manages to prepare a meal. How long does it take? Does it cause their fatigue to worsen? How do they feel after? How long can they stand for? Can they chop and peel vegetables? Does this increase their pain? Do they have any aids? If they report a lack of motivation, do they require prompting? Are there any cognitive restrictions? Are they safe in the kitchen?

Activity 2: Taking nutrition

Normal eating and drinking can be challenging for example if all of stomach and oesophagus have been removed or in head and neck cancer surgery for example where swallowing is difficult, or tongue removed. This may impact on energy levels to undertake activities of daily living. There may also be a lack of motivation with prompting need, in addition to severe nausea/vomiting and lack of appetite due to the condition and any treatment such as chemotherapy.

Remember in PIP…

Can someone chew, swallow and bring food to their mouth? Are there any risks of choking? Do they require a soft diet? Do they use adapted cutlery? If they report extensive symptoms/side effects from treatment, does this impact their appetite? Do they subsequently require prompting to eat?

Activity 3: Managing therapy and monitoring a health condition

Depending on the cancer there may be injections, regular medication, permanent catheters for treatment (e.g. PICC or Hickman line), inhalers, dressings, compression garments/bandages, etc. Many are likely to require support due to cognitive effects, psychological effects or physical effects causing pain and fatigue.

Remember in PIP...

If people have therapy in the home environment, do they require assistance with this? If so, is this occurring on the majority of the year? How long does the assistance take? Furthermore, can they manage their medications? Can they remember to take them and physically obtain them from the packaging?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and bathing

The type of cancer will affect the impact of any pain, fatigue and other affecting symptoms. Some may struggle to balance, have poor range, poor sensation and therefore control of limbs and grip or have hypersensitivity and struggle to and apply pressure and feel water such as from a shower on their skin. There may also be psychological impact causing apathy and poor motivation or cognitive impacts from medication or due to tumour site such as brain tumours. Some experience lymphoedema of a limb and struggle with the weight of it. Others will have associated mental health restrictions.

Remember in PIP…

It is imperative to explore how someone manages to wash. How long does it take? Does it cause their fatigue to worsen? How do they feel after? How long can they stand for? Can they get in and out of the bath? Does this increase their pain? Do they have any aids? If they report a lack of motivation, do they require prompting?

Activity 5: Managing toileting needs and incontinence

Continence problems and sexual dysfunction can affect some people. Many might have a stoma.

Remember in PIP…

You must explore how someone sits on, stands from and cleans themselves after using the toilet. Furthermore, if they experience incontinence, is this on the majority of days? Is this bladder and bowel? Can they self manage or do they require assistance?

Activity 6: Dressing and undressing

The type of cancer will affect the impact of any pain, fatigue and other affecting symptoms. Some may struggle to dress due to poor range, poor sensation and therefore control of dexterity and grip for dressing. Some have hypersensitivity and struggle to apply pressure and managing fastenings. There may also be psychological impact causing apathy and poor motivation or cognitive impacts from medication or due to tumour site such as brain tumours. Some experience lymphoedema of a limb and struggle with the weight of it. Others will have associated mental health restrictions.

Remember in PIP…

It is imperative to explore how someone manages to dress. How long does it take? Does it cause their fatigue to worsen? How do they feel after? Can they complete it whilst seated? Can they manage fastenings? Does this increase their pain? Do they have any aids? If they report a lack of motivation, do they require prompting?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating verbally

The type of cancer will affect the impact of any communication restrictions. Some may have cognitive impact which reduces their ability to understand, process and verbalise, or speech may be slurred and have poor clarity or volume.

Remember in PIP...

You need to consider someone's ability to both express **and** understand verbal communication. They may have cognition, but can they reliably express themselves? Do they require assistance to communicate their needs? How long does it take them to express a basic sentence? If there are cognitive restrictions, what is their level of understanding? Do they require support to break down information?

Activity 8: Reading and understanding signs and symbols

The type of cancer will affect the impact of any reading restrictions such as cognitive impairment, visual distortion or other comorbidities.

Remember in PIP…

This is the ability not only to read written information, but also understand it. Are they reading comics/magazines with little understanding of the context? Could they read a text message?

Within the scope of PIP, complex written information is more than one sentence.

If someone has a visual impairment, can they read normal size font? Do they require the use of aids other than prescription spectacles? Can they reliably use aids, or do they require assistance to read?

Activity 9: Engaging with others face to face

The type of cancer will affect the impact of any social engagement.

Remember in PIP…

If they report restrictions engaging, how does this manifest? How do they engage with familiar and unfamiliar people? Do they experience any anxiety? How do they manage this? If they report difficulties engaging with unfamiliar people, who can support them? If someone specific is reported, why is this?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

The type of cancer will determine the impact on their ability to budget as some will experience cognitive effects from medication or site of tumour. Others will have associated mental health restrictions.

Remember in PIP…

Can they manage both basic and complex budgeting? Would they understand what change to expect in a shop? Can they plan for future budgeting? Could they manage a household bill? Do they need support with any areas of budgeting? Do they lack motivation to manage bills?

Activity 11: Planning and following a journey

The type of cancer will determine impact on their ability to plan and follow a journey. There may be cognitive restrictions from medication or site of tumour, sensory impacts and associated mental health considerations.

Remember in PIP…

Can they do this activity safely? How do they manage familiar and unfamiliar journeys? How would they cope with a diversion? Can they use public transport? If they report anxiety, does this meet the threshold of OPD? If so, how often are they able to go out of the home with support? Do they experience OPD on both familiar and unfamiliar journeys? Do they require support to overcome this?

Activity 12: Moving around

The type of cancer will affect the impact of any physical restrictions. Pain and fatigue are likely to have a impact, some may experience lymphoedema of a limb and struggle with the weight of it, others may have poor control of their limbs, or have balance restrictions.

Remember in PIP...

Lived examples help to paint a clear picture of function to the Department. Where can they walk? How long does it take? Do they have falls? Can they repeat? Do they use aids? Have they had falls? Do they have pain? How do they feel after walking any distance? Do their symptoms worsen as the day progresses?

Additional reading or other resources

EXTERNAL

An overview of cancer:

- RCGP consequences of treatment toolkit - https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/consequences-of-cancer-toolkit.aspx
- Consequences of treatment - https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/consequences-of-treatment
- Macmillan webpages - https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/consequences-of-treatment
- Macmillan information - https://be.macmillan.org.uk/be/s-190-resources-for-health-and-social-care-professionals.aspx?_ga=2.197123180.1772690613.1550493685-1693358207.1539607685
- Primary care/GP resources - https://www.macmillan.org.uk/about-us/health-professionals/resources/resources-for-gps.html

Surgery:

- Managing fatigue - primary care ten top tips
- Understanding lymphoedema [PDF]

Chemotherapy and targeted therapy:

- https://www.macmillan.org.uk/_images/endocrine-late-effects_tcm9-340519.pdf

Radiotherapy:

- Guidance on long term consequences of treatment for gynaecological cancer
- Managing the late effects of breast cancer treatment [PDF]
- Managing the late effects of bowel cancer treatment [PDF]
- Managing the late effects of head and neck cancer [PDF]
- Managing the late effects of pelvic radiotherapy in men [PDF]
- Managing the late effects of pelvic radiotherapy in women [PDF]

Additional reading or other resources

INTERNAL

- Desktop Aid – Cancer, Fatigue, Breathlessness, Activity 12, Activity 11

Version control