

There is so much we don't know in medicine that could make a difference, and often we focus on the big things, and the little things get forgotten. To highlight some smaller but important issues, we've put together a series of pearls that the Red Whale found at the bottom of the ocean of knowledge!



Working with Macmillan Cancer Support

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UKONS tool

The UKONS tool has existed for some time in a format that was suitable for secondary care. It was used as a triage tool by oncology nurses manning the 24-hour helplines. Macmillan Cancer Support and the UK Oncology Nursing Society have created an adapted version for primary care, recognising that we need a lower threshold for concern.

Who is it for?

The tool is suitable for all patients who:

- Have received systemic anticancer therapy (including immunotherapy).
- Have had radiotherapy.
- Are at risk of disease-related immunosuppression (e.g. haematological malignancies).

Why is it needed?

All patients receiving systemic anticancer treatment will be given access to a 24-hour advice line and asked to contact this number if they are worried. The vast majority of patients **will** contact this number, but it is increasingly recognised that:

- Some may not recognise the significance of their symptoms.
- Some may report not knowing who to contact (*we need to direct them*).
- Delayed symptoms, such as those seen with immunotherapies, may present even 12 months after treatment has finished, and may throw both patients and clinicians.

How to use the tool

- Identify and record your local advice line numbers (this is the most important thing because, in reality, the tool recommends contacting these numbers in the event of most symptoms).
- The tool is based solely on presented symptoms. You do not need to know the details of treatment, e.g. which agents are being used or what cycle.
- If symptoms that are not contained within the tool are reported, the creators suggest seeking specialist advice.
- The tool can be used to grade the severity of the presented symptom AND as a checklist for unreported symptoms.
- The tool grades symptoms into three groups:

GREEN	These 'symptoms' are suitable for close monitoring by the patient.
AMBER	Discuss with the advice line as soon as possible.
RED	Contact advice line immediately, which will arrange clinical review. (On occasion, it recommends bypassing the advice line and referring directly to A&E, e.g. chest pain, haemorrhage, severe infection.)

- If the presenting problem is green, the tool suggests we use the symptoms as a checklist to ensure there are no unreported symptoms.
- If the patient scores green in ALL toxicities, they can be reassured (*though, from our point of view in primary care, we might want to consider non-cancer treatment causes!*).



Did you know that Macmillan provide a wealth of useful information for primary care professionals? Take a look through their quarterly e-newsletter, Primary Care Update and check out the range of useful resources on their Support page!

Support for Primary Care: www.macmillan.org.uk/gp

Primary Care Update e-newsletter: www.macmillan.org.uk/about-us/health-professionals/news-and-updates/primary-care-update.html#322227

BACKGROUND

Primary Care Risk Assessment Tool for Oncology Haematology Patients who are:

- **Receiving or received systemic anti-cancer therapies.**
- **Receiving or recently received radiotherapy.**
- **At risk of disease related immunosuppression.**

It is important that the side effects of treatment are not underestimated and that the significance of symptoms is recognised.

This evidence-based risk assessment tool grades the presenting symptoms and advises action accordingly using a RAG system. It is important that the significance of lower level amber toxicities are recognised.

Systemic anti cancer therapy is an overarching term that includes cytotoxic chemotherapy, immunotherapy, monoclonal antibodies and new novel therapies.

RISK ASSESSMENT PROCESS

All patients receiving Systemic Anti-Cancer Therapy are provided with a 24 hour advice line telephone number. We recommend that you use this tool to risk assess any symptom the patient mentions to you. Patients might only report symptoms that are most worrying to them, and not mention others that may be significant. It is very helpful to use the risk assessment as a quick checklist to identify any potential problems.

If the patient scores **RED** or **AMBER** for any symptom, you should contact the **24 Hour Advice Line** immediately for a full triage assessment, unless **URGENT** referral to A&E is advised.

Patients may require urgent assessment in a suitable clinical area that provides access to investigation and treatment facilities. The advice line team will arrange assessment and/or further monitoring for the patient, if they feel it is required.

Please be aware that the period of time that patients may experience post treatment side effects/complications may vary according to the treatment they have received, and can be as late as 12 months post treatment.

Patients may present with problems other than those listed below. Be cautious, and if in doubt about anything contact the advice line.

The information contained in this guide is a consensus of the development and consultation group's expert opinions on current treatment. Clinicians using this guide are expected to use independent clinical judgment in the context of the presenting clinical circumstances to determine any patient's care or treatment.

In partnership with Macmillan Cancer Support.



Please note: If patient is having or has received immunotherapy within the last 12 months or is taking Capecitabine, refer to advice line for review. Please ask patient to delay any oral treatment until they have had advice line review.				
TOXICITY	If your patient scores RED or AMBER for any toxicity you should contact the 24 Hour Advice Line immediately for a full triage assessment.			
Fever and/or generally unwell AND received systemic anti-cancer therapy (chemotherapy oral or I.V.) within the last 6 to 8 weeks, or is at risk of disease related immunosuppression.	If temperature is > 37.5 °C or < 36 °C or generally unwell, contact telephone advice line for URGENT assessment. <i>Risk of neutropenic sepsis.</i> ALERT - Patients on steroids/analgesics or who are dehydrated may not present with pyrexia but may still have infection. <i>If in doubt phone for advice.</i>			
Fever In patients who have NOT received oral or I.V systemic anti-cancer therapy within the last 6 weeks or are NOT at risk of disease related immunosuppression.	No fever, 36.0 °C - 37.4 °C	> 37.5 °C - 38 °C	> 38 °C - 40 °C	
Anorexia How much are they eating and drinking? Any recent weight loss? Any contributory factors e.g. diarrhoea, vomiting, nausea or mucositis? If yes, see below for specific problem.	None or no change from normal.	Loss of appetite without alteration in eating habits.	Oral intake altered without significant weight loss or malnutrition.	Oral intake altered in association with significant weight loss/malnutrition. Possible life threatening complications e.g collapse.
Bleeding Is it a new problem? Is it continuous? What amount? Where from? Is the patient on anticoagulants or antiplatelets? If your clinical assessment gives concern about active blood loss, arrange URGENT A&E attendance for medical assessment.	None or no change from normal.	Mild, self-limited controlled by conservative measures.	Uncontrollable haemorrhage - if haemodynamically unstable and/or large volume blood loss - <i>consider 999.</i>	
Bruising Is it a new problem? Is it local/generalised? Is there any trauma involved?	None or no change from normal.	Petechiae/bruising, localised.	Moderate petechia/purpura. Generalised bruising.	Generalised petechia/purpura. Generalised bruising.
Chest pain Onset? What makes it worse? Radiation? Any cardiac history?	None or no change from normal.	<i>URGENT A&E attendance for medical assessment 999.</i> A number of chemotherapy drugs are cardiotoxic, there is also an increased risk of pulmonary embolism in this group of patients - urgent assessment is recommended.		
Confusion/cognitive disturbance Is this a new symptom? Is it getting worse & when did it start? Is it constant? Has there been a recent change in medication? Is it associated with any other symptom? If yes, please see specific symptom?	None or no change from normal.	Mild disorientation not interfering with normal activity. Slight decrease in level of alertness.	Moderate disorientation and/or cognitive disability limiting normal activity.	Severe cognitive disability and /or confusion; severely limiting activity/ function. Altered level of consciousness - loss of consciousness. <i>999 - urgent A&E assessment.</i>
Constipation How long since bowels opened? What is normal? Any abdominal pain/vomiting? Has the patient taken any medication such as opiates? <i>Consider obstruction and/or perforation.</i>	None or no change from normal.	Mild - no bowel movement for 24 hours over pre-treatment normal. Advice - Dietary advice, increase fluid intake, review supportive medication.	Moderate - no bowel movement in last 48 hours over pre-treatment normal.	Severe - no bowel movement in last 72 hours or more over pre-treatment normal.
Diarrhoea How many days has this occurred for? How many times in a 24 hour period? Any blood or mucous in stool? Has the patient taken any anti-diarrhoeal medication? Does the patient have any abdominal pain/ discomfort? For how long? See specific toxicity for pain if applicable.	None or no change from normal.	Increase of up to 3 bowel movements a day over pre-treatment movements or mild increase in ostomy output.	Increase of 4 or more episodes a day over pre-treatment normal or moderate increase in ostomy output. Nocturnal or new incontinence. Moderate to severe cramping. Bloody diarrhoea.	
			Patients who are receiving or have received immunotherapy in the previous 12 months are at risk of treatment related colitis and should be managed promptly. Always contact the advice line.	
Urinary Disorder Is this a new problem? Is there any change in urine colour? Any blood in the urine? Any new incontinence, frequency or urgency? Are they passing normal amounts? Drinking normally? Thirsty? <i>Consider hypercalcaemia.</i>	None or no change from normal.	Mild to moderate symptoms, with an increase in frequency, urgency, dysuria or nocturia. Some reduction in output.	Severe symptoms with severe reduction in urine output. Possible retention/obstruction. New incontinence. New or increasing haematuria.	
Dyspnoea/shortness of breath Is it a new symptom? Is dyspnoea worsening? Is there any chest pain? - link to specific toxicity. What can the patient do? (Alteration in performance status.) <i>Consider SVCO / Anaemia / Pulmonary Embolism / Pneumonitis etc.</i>	None or no change from normal.	New onset shortness of breath with moderate exertion.	New onset shortness of breath on minimal exertion and / or shortness of breath at rest.	



Advice line number

Advice line numbers will differ across the country - contact your oncology or acute oncology service to identify your local number before adding here.

Please note: If patient is having or has received immunotherapy within the last 12 months or is taking Capecitabine, refer to advice line for review. Please ask patient to delay any oral treatment until they have had advice line review.

TOXICITY	If your patient scores RED or AMBER for any toxicity you should contact the 24 Hour Advice Line immediately for a full triage assessment.			
Extravasation - drug leakage around infusion site or along infusion pathway Has the patient got pain, soreness or ulceration around or along the infusion pathway/injection site/central venous catheter?	None.	History of receiving intravenous infusion via central venous line or peripheral cannula with pain, burning, soreness and/or inflammation or swelling around or along infusion site pathway. Certain chemotherapy drugs can cause long term severe tissue damage if extravasation occurs.		
Infection - what is the patients temperature? If abnormal see fever above. Patients who are receiving chemotherapy or are at risk of immunosuppression that have any signs/symptoms of infection, should be referred to the advice line for assessment.	None.	Generally well with localised signs of infection.	Generally unwell with signs/symptoms of infection. <i>If there are signs of severe symptomatic infection consider possible life threatening sepsis and dial 999 for urgent A&E assessment.</i>	
Nausea and/or Vomiting How many days/episodes? What is the patient's oral intake? Is the patient taking antiemetics as prescribed? Assess patient's urinary output. Does the patient have constipation or diarrhoea? (see specific toxicity)	None.	Mild symptoms - able to eat/drink with reasonable intake and/or 1 episode of vomiting in 24 hours. <i>Advice - review antiemetics and ensure patient is taking as prescribed.</i>	Can eat/drink but intake significantly decreased and/or 2-5 episodes of vomiting in 24 hours.	No significant intake and/or 5 or more episodes of vomiting in 24 hours.
Neurological symptoms (sensory and/or motor) When did the problem start? Is it continuous? Is it getting worse? Is it affecting mobility/function? Any constipation or urinary or faecal incontinence? <i>Does the patient have back pain? Consider spinal cord compression.</i>	None.	Any of the following signs or symptoms - mild paraesthesia, subjective weakness with no objective findings, back pain.	Mild or moderate sensory loss, moderate paraesthesia, mild weakness with no loss of function with or without back pain.	Severe sensory loss, paraesthesia or weakness that interferes with function with or without back pain. Any evidence of paralysis. <i>Consider 999 - treat as unstable spine.</i>
Oral/Stomatitis - Sore Mouth How many days? Is there evidence of mouth ulcers? Is there evidence of infection? Are they able to eat/drink? Assess patient's urinary output.	None.	Painless ulcers, erythema, mild soreness, able to eat/drink. <i>Advice - use mouthwash as recommended.</i>	Painful erythema, oedema or ulcers but can eat/drink.	Painful erythema, difficulty with eating and drinking and/or mucosal necrosis. Patient may require parenteral or enteral support.
Pain Is it a new problem? Where is it & when did it start? Any analgesia? <i>Consider thrombosis - any swelling/redness? Back pain - consider spinal cord compression. Headache - consider brain metastases.</i>	None or no change from normal.	Mild pain. Not interfering with function. <i>Advice - analgesia review.</i>	Moderate pain. Pain interfering with function and/or daily activities.	Severe pain that may be disabling and/or interfering with activities of daily living.
Red hands and/or feet (palmar - plantar syndrome) This may be a side effect of certain chemotherapy treatments and requires specific action to be taken.	None.	Numbness, tingling, erythema or swelling of hands and/or feet, with or without pain.		Moist desquamation, ulceration, blistering and severe pain.
Performance status and/or Fatigue Has there been a recent change in performance status/activities of daily living? How many days has this occurred for? Any other associated symptoms? If yes, see specific symptom.	No recent change from patients normal.	Symptomatic but completely ambulant. Increased fatigue but not affecting normal activities. Ask the patient to discuss this with their key worker. <i>N.B. If receiving or received immunotherapy then please see below.</i>	Symptomatic, but ambulatory and capable of all self care, but unable to carry out any work activities. Up and about more than 50% of waking hours. Moderate or severe fatigue causing difficulty or loss of ability to perform some activities.	Symptomatic, capable of only limited self care, confined to bed for more than 50% of waking hours or completely bed or chair bound. Disabling fatigue or bedridden.
Patients who are receiving or have received immunotherapy in the previous 12 months are at risk of treatment related endocrinopathies, any new or increasing fatigue should be investigated. Please contact the advice line.				
Rash Is the patient systemically unwell? Is it localised or generalised? How long has it been there? Any signs of infection, such as pus or pyrexia? Is it itchy? For haematology patients, contact haematology team.	None or no change from normal.	Rash covering less than 10% of the body surface (mild) with or without other symptoms, pruritis, burning, tightness.	Rash covering greater than 10% of the body surface area: with or without symptoms. Or bleeding with or without trauma. Or signs of infection. Or generally unwell.	
Ocular/eye problems Any pain, redness, visual disturbance or discharge.	None or no change from normal.	Mild symptoms not interfering with function.	Moderate to severe symptoms, interfering with functions or any visual disturbance.	