

Developing an exemption definition for the ESA Work Capability Assessment

Findings from an Expert Consultation

May 2011

Prepared for Macmillan Cancer Support

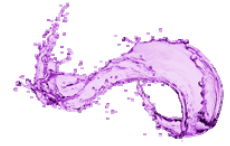
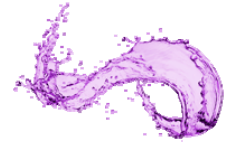


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1. Background to the consultation

One of Macmillan's current influencing priorities is to improve the way that cancer patients access Employment and Support Allowance (ESA). Under the current rules, there are some people who are exempt from having to go for the medical assessment, and are automatically placed in the Support Group (where there are no conditions attached to receiving the benefit). Those are people who are:

- terminally ill (i.e., their death can reasonably be expected within six months);
- receiving, or recovering from, intravenous, intraperitoneal or intrathecal chemotherapy;

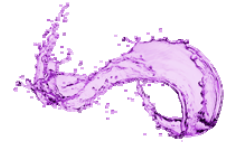
However, cancer patients receiving oral chemotherapy are not exempt, and have to go through the medical assessment, even though their condition may be just as debilitating as someone receiving non-oral chemotherapy. Similarly, those receiving radiotherapy are also not exempt. Macmillan believes this differentiation between cancer treatments is unfair, and does not have a clinical justification.

In 2010 an independent review of the Work Capability Assessment (WCA), the assessment process for determining eligibility for ESA, was carried out, led by Professor Malcolm Harrington. As part of this review Macmillan recommended that existing ESA cancer exemptions should be extended to oral chemotherapy and radiotherapy patients.

Professor Harrington accepted Macmillan's general point that the existing exemptions needed to be improved and in order to inform the 2nd annual independent review of the WCA, has specifically asked Macmillan to make recommendations about how the assessment process could be improved. Professor Harrington will then make recommendations to the Government.

In order to gain a clinical perspective on the approach of differentiating between patients on the basis of their treatment regime, Macmillan need to consult with and obtain the views of senior cancer clinicians. The aim is to provide the independent review with a strong, authoritative, and consensual medical opinion about how the exemptions can be improved.

In order to meet this objective, an Expert Consultation was held to enable a range of clinicians from various specialisms to participate.



2. Methodology

The approach for the Expert Consultation was based on the core principle that there would need to be dialogue and debate between senior clinicians in order to arrive at a consensus in terms of the definition for exemptions.

Beyond that a number of practical considerations dictated the final approach selected:

- Senior clinicians are exceptionally busy, with a large number of demands on their time. The impossibility of coordinating, at relatively short notice, the schedules of those interested in participating precluded a focus group approach
- We wished to ensure that clinicians from across the UK were able to participate
- The timing of the consultation phase fell immediately after the extended Easter and 'bank holiday' period which inevitably reduced the availability of clinicians.

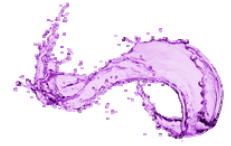
For these reasons, we selected an online approach that would allow clinicians to participate in their own time, over an extended period of days. This enabled all those interested to participate in the consultation.

In order to further increase the flexibility of participating, a three phase approach was selected:

1. RS Consulting's bespoke **online portal** was used to pose a series of questions for senior clinicians to complete individually, in their own time. These questions did not require interaction or discussion but formed the basis of understanding about various treatments and their relative impact in terms of debilitation which would form the basis of the main phase of the consultation. At this stage, all responses remained confidential. RS Consulting and Macmillan were able to monitor responses on a daily basis with a view to seeking clarification or additional information as necessary.
2. An **online 'bulletin board'** in the week following the completion of the individual questions. An online bulletin board enables respondents to interact with each other and see the responses posted by everyone to a series of questions. This phase was used to summarise the responses provided in phase 1 and to iteratively work towards exemption definitions based on a number of criteria. RS Consulting and Macmillan responded the information and opinions shared on the bulletin board on a daily basis to seek further clarification and refine the proposed exemption definitions
3. **Agreement with the final proposed definition** – Following the closure of the online bulletin board, Macmillan developed the final proposed exemption definition based on all the information obtained throughout the consultation. This definition was then emailed to all those who had participated (and two interested clinicians who had not been able to participate) for final confirmation of their support and agreement with it.

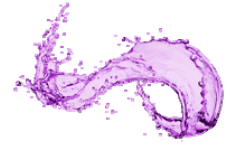
The consultation was conducted over two weeks in May 2011. The online portal was open 3rd – 8th May inclusive and the bulletin board discussion was live from 9th - 15th May.

All research was conducted in compliance with ISO20252:2006.



3. The panel of experts

Macmillan invited a number of senior clinicians and cancer care professionals to participate in the consultation.



4. Overview of the debate

4.1 Chemotherapy

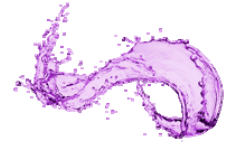
Currently, patients undergoing awaiting, receiving or recovering from treatment by way of intravenous, intraperitoneal or intrathecal chemotherapy are exempt from the Workplace Capability Assessment whilst those waiting, receiving or recovering from treatment by way of oral chemotherapy are not.

In order to explore whether or not this distinction based on the treatment mode is justified, the consultation explored the side-effects and debilitating impacts of oral chemotherapy and sought views on whether or not the distinction has a clinical basis.

4.1.1 The debilitating side-effects of oral chemotherapy

A wide range of debilitating side-effects is caused by oral chemotherapy and it is not the intention of this report to produce a comprehensive overview of these as there is a large body of literature that covers this in far more detail and depth than is possible here. Nonetheless, it is worth highlighting the main debilitating side-effects and these are listed below, roughly in order of the number of mentions by the expert participants.

- Fatigue – identified by almost all as a very common side-effect that can frequently last for months (or years) beyond the end of treatment. Fatigue is also cumulative and a patient is likely to be increasingly fatigued as they progress through successive treatment cycles. A related side-effect is lack of concentration/lack of mental stamina/difficulty in making decisions. Weight-loss can further contribute to this.
- Sickness (nausea and/or vomiting) - as with fatigue, this is a very common side-effect but one which typically resolves more rapidly (within a few days) of treatment finishing.
- Diarrhoea – can mean that many patients feel unable to go far from home as they need to be near appropriate facilities
- Oral sensitivity/ mucositis – The effects of mucositis can vary considerably, ranging from mild soreness of the mouth to extreme break down/ulceration of the mouth and gastric mucosa and severe discomfort/pain.
- Loss of appetite – this often occurs as a result of taste changes, nausea, diarrhoea and mucositis. This can result in weight loss.
- Neuropathy - Nerve end damage that typically affects hands, feet and lower legs that can make it difficult to hold small objects such as a pen. As with many other side-effects, neuropathy often worsens as treatment progresses.
- Plantar Palmar Erythema (hand- foot syndrome) – This side effect is graded 1-3 and ranges from mild tingling, skin redness & dryness of the just the hands, which does not affect the patient's ability to perform activities of daily living, to that of severe moist desquamation, ulceration, blistering and pain affecting hands and feet resulting in an inability to walk or perform activities of daily living.
- Sensitivity to cold which make it difficult to go outside & breathe in cold air, hold metal objects, clean teeth and open the fridge.
- Hair loss – This can make patients self-conscious and less confident.
- Risk of infection. This can be profound in some regimens and can be debilitating as patients are advised to avoid contact with people with infections and crowded areas.



Overall, the general consensus is that almost all patients will experience at least one of these symptoms to some extent.

However, the experts note that the likelihood of experiencing a specific side-effects, and the extent to which that side-effect would be severely debilitating, vary according to a number of factors:

- The specific drug prescribed, specifically with reference to:
 - ◆ The toxicity of the drug
 - ◆ The dosage
- The duration of treatment – almost all experts note that side-effect typically become more debilitating as treatment progresses due to the cumulative toxicity building up in a patient
- The underlying health status of the patient (co-morbidities, age etc.)

With this in mind, the majority of experts agree that oral chemotherapy is generally a good proxy for debilitation. The one exception to using oral chemotherapy as a proxy for debilitation is where it is being administered as a long-term maintenance therapy, for example imatinib in chronic lymphocytic leukaemia.

4.1.2 The route of administration as a proxy for debilitation

There is a clear consensus that the route of chemotherapy administration is not a good proxy for determining likely debilitation and clinicians can provide a number of examples where an oral chemotherapy drug is more toxic (and hence typically more debilitating) than its IV equivalent or where the same drug can be administered through either route with the same impacts. The exception to this is where oral chemotherapy is administered as a long-term maintenance therapy, as noted in Section 4.1.1.

4.1.3 Expert support for statements relating to chemotherapy

Based on the opinions expressed in Phase 1 of the research, as summarised in Sections 4.1.1 and 4.1.2, a number of statements were proposed and the expert participants were asked to indicate whether or not they agree with each.

Statement 1

"The route of administration for chemotherapy (i.e. oral vs. non-oral) is not a good proxy for the level of debilitation that a patient will experience."

Ten participants responded to and agree with this statement.

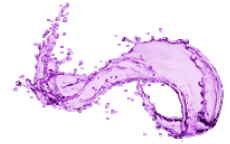
Statement 2

"The severity of debilitation experienced as a result of chemotherapy is primarily driven by four main factors:

- *The toxicity of the specific chemotherapy drug*
- *The length of time that the drug is administered for*
- *The dosage*
- *The underlying health status of the individual patient"*

Ten participants responded to and agreed with this statement.

In addition, participants wished to highlight that other, less clinical or tangible factors can also impact on the severity of side-effects experienced and a patient's ability to cope with treatment. These include their emotional status, their social and emotional support network, their personal/ domestic situation (i.e. living alone vs. with family; caring responsibilities etc.) and their financial situation.



4.1.4 Developing an exemption definition for patients undergoing chemotherapy

The experts participating in Phase 2 of the consultation were challenged to develop an exemption definition for patients undergoing chemotherapy that is both an appropriate proxy for debilitation and workable in practice. A number of potential criteria were proposed and ideas progressively evolved based on feedback shared between professionals and on input provided by RS Consulting and Macmillan.

A summary of the main ideas, and the reasons for their rejection, is below:

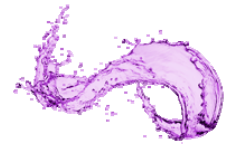
- *“Any patient receiving courses of chemotherapy and / or immunotherapy which carry a more than 10% risk of febrile neutropenia.”* – This idea was considered to not be sufficiently workable in practice because:
 - ◆ Patients are extremely unlikely to know this information
 - ◆ This information may not be readily available for all drugs, and the list of drugs is constantly evolving
- *“Treatment that in the opinion of the treating physician is likely to cause significant debility.”* – This idea was rejected as the objective is for patients to avoid physician assessment at this stage of the application process
- *“Any treatment that includes/requires additional supportive therapies, i.e. if anti-emetics and/or GCSF or immodium are needed then the treatment is sufficiently toxic to qualify.”* - This idea was considered to not be sufficiently workable in practice because of the difficulty for patients in identifying whether drugs they are taking are considered to be “additional supportive therapies”.
- *“All patients”* – This idea was rejected as the majority of experts participating felt that the definition should exclude those undergoing long-term maintenance therapy

From this final point, the definition evolved on the basis of seeking a way to include all patients except those undergoing long-term maintenance therapies. After some discussion around the ability of patients to differentiate between long-term treatments and maintenance therapies, a consensus emerged that the most workable definition would be around the duration of treatment, with more than six months considered to be an appropriate proxy.

This discussion formed the basis of the final exemption definition developed for patients undergoing chemotherapy.

A patient should be automatically exempt from going through an assessment if they are:

- Awaiting, receiving or recovering from treatment by way of intravenous, intraperitoneal or intrathecal chemotherapy; or
- Awaiting, receiving or recovering from treatment by way of oral chemotherapy, except when the therapy is continuous for a period of more than six months



4.2 Radiotherapy

Currently, patients undergoing awaiting, receiving or recovering from treatment by way of radiotherapy are not automatically exempt from the Workplace Capability Assessment.

As with oral chemotherapy, Macmillan wished to explore whether or not the side-effects of radiotherapy are sufficiently debilitating to justify an automatic exemption as well.

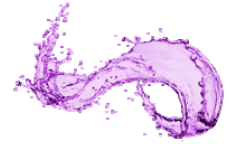
4.2.1 The debilitating side-effects of radiotherapy

As with chemotherapy, there is wide range of debilitating side-effects caused by radiotherapy but it is not the intention of this report to produce a comprehensive overview of these. When exploring the issue of debilitation as a result of radiotherapy with the experts, it immediately became apparent that the extent of debilitation is dependent on a number of factors:

- The tumour site being treated – this was spontaneously mentioned by all experts as a determinant in the level of debilitation that could be expected. A number of specific tumour sites were mentioned:
 - ◆ Head and neck
 - ◆ Gastro-intestinal
 - ◆ Pelvic
 - ◆ Colo-rectal
 - ◆ Total body irradiation
 - ◆ Lung
- The duration and dosage of treatment
- The underlying health status of the patient (co-morbidities, age etc.)
- The ‘intent’ behind the treatment – it was suggested that treatments given with curative and palliative intent tend to vary in duration and ‘dosage’ and hence more aggressive courses of treatment for curative intent tend to result in more (and more debilitating) side-effects.

Notwithstanding the huge variation possible in side-effects as a result of the factors identified above, there are a number of side-effects that warrant highlighting:

- Fatigue/ somnolence – identified by almost all as a very common side-effect that can frequently last for months (or years) beyond the end of treatment, regardless of tumour site. This is likely to affect the vast majority of patients, although the extent to which is severely debilitating will vary between individual patients.
- Bowel/ urinary problems (associated with pelvic cancer) – the majority of patients will experience diarrhoea during treatment and for some weeks after; a small minority will experience chronic (possibly permanent) radiation proctitis
- Cystitis/ thrush – associated with gynaecological cancers
- Dysphagia – mainly associated with head and neck, and gastro-intestinal cancers. This can result in loss of appetite and physical inability to eat, leading to weight loss and potentially malnutrition. A minority of patients may not regain the ability to eat and will require long-term tube feeding.
- Nausea – mainly associated with gastro-intestinal and pelvic cancers and, as with dysphagia, can result in a loss of appetite and reduced food intake
- Oral problems – such as change in taste, mouth ulcers, mucositis and soreness. Dependent on the precise area being treated, radiation therapy can also result in damage to teeth, muscles or jaw



bone, causing difficulties chewing and eating. This can have similar effects to dysphagia and nausea in terms of food intake.

- Sore skin/ blistering/ burns – this may affect any patient, regardless of tumour site, and is likely to continue for a few weeks post-treatment. In certain cancers (for example colo-rectal or pelvic cancers) this can be particularly debilitating as it can mean that even sitting or having clothing in contact with the affected area can be extremely painful.
- Breathlessness and pneumonitis – specific to lung cancer patients, typically peaking around six weeks post-treatment

As with chemotherapy, the effects of radiotherapy are cumulative, with side-effects typically becoming more severe as treatment progresses.

In addition, and as with chemotherapy, some experts wished to highlight that other factors can also impact on the severity of side-effects experienced and a patient’s ability to cope with treatment. These include their emotional status, their social and emotional support network, their personal/ domestic situation (i.e. living alone vs. with family; caring responsibilities etc.) and their financial situation. The time required for travel to and attendance at daily appointments was also highlighted as a factor that has a major impact on a patient’s ability to continue a normal daily life.

4.2.2 The relative debilitation of radiotherapy compared with chemotherapy

Given the complex range of factors that affect the level of debilitation from both radiotherapy and chemotherapy, experts unsurprisingly struggle to draw general comparisons between the two types of treatment.

At an overall level, however, no expert believes there is an argument for suggesting that one type of treatment is more debilitating than another and consider that there are circumstances under which chemotherapy will be more debilitating than radiotherapy (for example breast cancer) and vice-versa (for example head and neck or pelvic cancer). Broadly speaking, the two types of treatment are considered to be comparable in terms of level of debilitation, if not in terms of the specific side-effects experienced.

For those patients undergoing treatment for the cancer types identified in Section 4.2.1, radiotherapy is identified as often more debilitating than chemotherapy for the same tumour site. It was also noted by some experts that increasingly the two treatment modes are used in conjunction for many tumour sites and so it becomes ‘academic’ to try and separate out the side-effects of each modality.

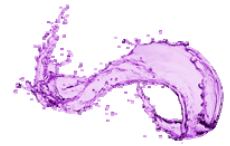
4.2.3 Expert support for statements relating to radiotherapy

Based on the opinions expressed in Phase 1 of the research, as summarised in Sections 4.2.1 and 4.2.2, a number of statements were proposed and the expert participants were asked to indicate whether or not they agree with each.

Statement 1

"Not all radiotherapy treatment is necessarily particularly debilitating but it can be severely debilitating in certain circumstances."

Eight participants responded to and broadly agree with this statement. However, it should be noted that “certain circumstances” was open to interpretation and two experts feel that radiotherapy is only ‘not particularly debilitating’ in a minority of cases.



Statement 2

"The severity of debilitation experienced as a result of radiotherapy is primarily linked to three main factors:

- *The tumour site being treated*
- *Whether the radiotherapy is with curative or palliative intent*
- *The length of the treatment period"*

Initially, eight participants responded to this statement and all were concerned that that statement relating to "curative or palliative intent" was not correct, believing that palliative regimens can be as debilitating as curative regimens. Many experts also feel that "the underlying health status of the patient is an important factor influencing debilitating and that it should be included.

The statement was therefore revised to:

"The severity of debilitation experienced as a result of radiotherapy is primarily linked to three main factors:

- *The tumour site being treated*
- *The length of the treatment period*
- *The underlying health status of the patient"*

Seven participants responded to and broadly agree with this statement. Further comments relating to concurrent chemo-irradiation therapy and also the emotional status of patients were also made. Chemo-irradiation is addressed separately in Section 4.3.

Statement 3

"Patients undergoing radiotherapy to treat the following tumour sites should be exempt from the Work Capability Assessment:

- *Head and neck*
- *Gastro-intestinal*
- *Pelvic (including gynaecological, prostate, testicular etc.)*
- *Colorectal"*

Initially, eight participants responded to this statement and highlighted that brain and lung tumours specifically should be added to the list, whilst testicular cancer should be removed.

The statement was therefore revised accordingly:

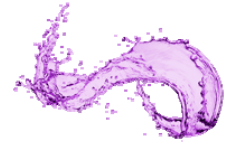
"Patients undergoing radiotherapy to treat the following tumour sites should be exempt from the Work Capability Assessment:

- *Head and neck (including brain)*
- *Gastro-intestinal*
- *Pelvic (including gynaecological, prostate, etc.)*
- *Colorectal"*

This statement is more acceptable to the experts and is deemed to capture those sites which are most likely to result in debilitation. Nonetheless, experts do not feel it would necessarily capture "almost all" patients experiencing severe debilitation due to the important influence of underlying health status and emotional well-being etc. on a patient's ability to cope with treatment.

4.2.4 Developing an exemption definition for patients undergoing radiotherapy

Although there was a broad consensus regarding the statements tested (Section 4.2.3), some debate continued around the workability of such a definition and the likely debilitation arising from radiotherapy for breast cancer patients in particular.



Further explanation was provided at this stage to clarify and emphasise that patients not captured by the automatic exemption would be individually assessed for their capability to work, and to underline the need for a universal definition that will be relatively easy to put in to practice.

With this in mind, a new definition was tested with experts:

“Not all radiotherapy patients should automatically be exempt. Radiotherapy patients should only be automatically exempt when:

- *They are undergoing a combined chemotherapy and radiotherapy schedule; and/or*
- *They are being treated for one of the following:*
 - o *Head & neck (including brain tumours)*
 - o *Lung cancer*
 - o *Gastro-intestinal*
 - o *Pelvic – gynaecological, rectal, prostate*

This is based on our understanding from your comments that:

- *Those patients undergoing treatment for one of the tumour sites mentioned above are ‘more likely than not’ to experience severe debilitation. In effect, this means that the criteria serve as a good enough proxy for debilitation that individual assessment is not necessary.*
- *Those patients undergoing treatment for other tumour sites are not ‘more likely than not’ to experience severe debilitation. In effect this means that whether they are severely debilitated would be best determined through an individual assessment. This assessment would identify those patients who are experiencing severe debilitation, including due to emotional and psychosocial factors.”*

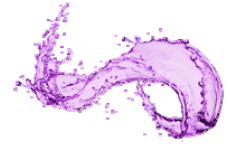
Eight participants responded to this statement and seven broadly agree with it, given the constraints of needing to ensure that a definition is workable, and on the proviso that the individual assessments would remain in place for all other patients undergoing radiotherapy.

Two experts continue to have reservations about whether such a definition is wide enough, but agree those included in the above statement should be included.

This discussion formed the basis of the final exemption definition developed for patients undergoing radiotherapy.

A patient should be automatically exempt from going through an assessment if they are:

- Awaiting, receiving or recovering from radiotherapy in the treatment in one or more of the following cancers:
 - ◆ Head and neck (including brain tumours)
 - ◆ Lung
 - ◆ Gastro-intestinal
 - ◆ Pelvic – gynaecological, rectal, prostate



4.3 Combined chemo-irradiation therapy

During the discussion and debate about the debilitation of chemotherapy and radiotherapy, several experts raised the point that one of the most severely debilitating treatment regimens is when a patient undergoes radiotherapy in combination with chemotherapy.

To ensure that this point was correct and agreed with by other experts, we asked participants in the consultation to indicate whether or not they agree with the following statement:

Statement 1

“Would you agree that all patients undergoing radiotherapy in combination with chemotherapy should be exempt from the ESA Work Capability Assessment? If not, why not?”

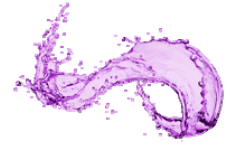
Eight participants responded to and agree with this statement.

This formed the basis of the final exemption definition developed for patients undergoing combined chemo-irradiation.

A patient should be automatically exempt from going through an assessment if they are:

- Awaiting, receiving or recovering from concurrent chemo-irradiation

It should be noted that the author of this report and Macmillan recognise that patients undergoing chemo-irradiation would already be covered by the other exemption definitions already proposed in Sections 4.1 and 4.2. However, as this particular treatment regimen is considered to be so particularly debilitating, we feel it warrants highlighting separately.



5. The exemption definition

Based on the outcome of the consultation, as discussed in Section 4, the following exemption definition was developed:

A patient should be automatically exempt from going through an assessment if they are:

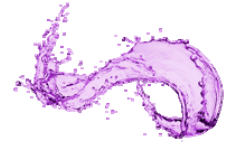
- terminally ill; or
- Awaiting, receiving or recovering from treatment by way of intravenous, intraperitoneal or intrathecal chemotherapy; or
- Awaiting, receiving or recovering from treatment by way of oral chemotherapy, except when the therapy is continuous for a period of more than six months; or
- Awaiting, receiving or recovering from concurrent chemo-irradiation; or
- Awaiting, receiving or recovering from radiotherapy in the treatment in one or more of the following cancers:
 - ◆ Head and neck (including brain tumours)
 - ◆ Lung
 - ◆ Gastro-intestinal
 - ◆ Pelvic – gynaecological, rectal, prostate

It is worth noting two specific points with respect to this definition:

- The phrasing of “awaiting, receiving or recovering from” has been chosen as it reflects the wording of the current exemption definitions for patients undergoing intravenous, intraperitoneal or intrathecal chemotherapy.
- The definition of ‘terminally ill’ remains as it is currently – i.e. a patient is not expected to live beyond six months and has been issued with a DS1500 by a healthcare professional

An email containing this definition was sent to the twelve experts participating in any stage of the consultation, and a further two experts who had been unable to participate in the phases 1 and 2.

Eight experts responded to the email and all concurred that they support the exemption definition as set out above.



6. Transcripts of the debate

6.1 Individual questions

The questions asked are set out below:

Chemotherapy

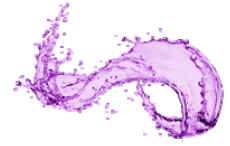
- 1 To what extent do you agree that all forms of chemotherapy are a reasonable proxy for likely debilitation? Please give reasons for your answer.
- 2 What would you say are the most common debilitating side-effects of oral chemotherapy?
 - How/in what way are these side-effects debilitating?And for each of these side-effects ...
 - Are there any typical variations in severity during the course of treatment?
 - What proportion of patients is affected by this?
 - How long do they typically last following treatment?
- 3 Overall, what proportion of patients under-going oral chemotherapy would be expected to experience at least one of these side-effects?
- 4 A key objective of this research is to understand the extent to which oral and non-oral chemotherapy could be considered to be equally debilitating. What is your view on this issue and why?
 - Are there any caveats to your broad view on this (for example, related to the duration of treatment or any other issue)?

Radiotherapy

- 1 Given that radiotherapy is not a systemic treatment, what are the factors that determine likely debilitation from radiotherapy?
 - What are the most debilitating forms of radiotherapy?
 - How/ in what way are these particular forms of radiotherapy debilitating?
- 2 What side-effects of radiotherapy in particular are debilitating?
And for each of these side-effects ...
 - Are there any typical variations in severity?
 - What proportion of patients is affected by this?
 - How long do they typically last following treatment?
- 3 How do the debilitating effects of radiotherapy compare to the effects of chemotherapy?
Are there situations when the effects of radiotherapy could be considered to be as debilitating as or more so than the effects of chemotherapy? If so, when/ why?

New & Emerging treatments

- 1 If you have experience of new or emerging treatments (for example biological treatments), which, if any, of these new treatments can result in high levels of debilitation?
 - What are the main side-effects?
 - What proportion of patients is affected by debilitating side-effects?
- 2 How do these treatments compare to chemotherapy and radiotherapy in terms of being debilitating for patients?



Supporting evidence

1 Macmillan is interested in any published studies or research in this area. Therefore, if you are familiar with any studies (for example, comparative studies of the side-effects of different treatments) and are able to provide us with the details, we would appreciate it.

2 If there is anything else that you would like to say on this subject at this stage, which has not been covered above, please use the box below.

Personal profile

Please can you explain in a few sentences your main area(s) of expertise and the area(s) in which you mainly work?

Please can you also tell us how long you have been working in cancer care?



e-luminate Senior Clinicians

Question: Chemotherapy	Sub-Question: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 08:52:26

This is true for the great majority of chemotherapy regimens but one area where there could be exceptions are long-term maintenance therapy for some conditions. These are most likely to involve oral therapies for some haematological cancers (ie Imatinib in chronic lymphocytic leukaemia) where people may be on treatment for many years and yet still be able to lead relative normal lives, including the ability to continue working.

Question: Chemotherapy	Sub-Question: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 07/05/2011 22:12:52

I think all forms of chemotherapy are a reasonable proxy for likely debilitation as patients can experience symptoms with all forms of chemotherapy including oral chemotherapy.

Question: Chemotherapy	Sub-Question: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 04/05/2011 12:47:48

Not in all situations : Oral chemotherapy drugs are not as toxic however, they do still have debilitating side effects such as neuropathy that can make work and life difficult . Some of these these side effects are short term.

Question: Chemotherapy	Sub-Question: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 13:24 18

Outpatient or oral chemotherapy may (paradoxically) be more debilitating than inpatient intravenous chemotherapy. Capecitabine+Oxaliplatin is an outpatient regimen but is both subjectively and objectively more toxic than its inpatient equivalent (oxaliplatin/De Gramont). Any chemotherapy is likely to be debilitating - this is a manifestation of its action on dividing cells in normal tissues and the consequent metabolic demands. There is absolutely no logic in discriminating between routes of administration when it comes to assessing fatigue.

Question: Chemotherapy	Sub-Question: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 08/05/2011 00:04:47



Some drugs and some combinations of chemotherapy are associated with more fatigue than others, but few even the self employed find it easy to work fulltime when having chemotherapy. It is not just the physical fatigue - its the mental fatigue/lack of concentration/lack of mental stamina/difficulty in making decisions. Even simple less toxic oral drugs like capecitabine if delivered for more than 2 months seem to have the same effect. The levels of fatigue seem to be quite individual, but in general younger fitter people suffer even more than older people.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	1	Senior Clinicians	[Redacted]

Posted On: 07/05/2011 22:01:55

I don't believe that all chemotherapy leads to debilitation and spend a considerable time with patients who have been scared by the lay perception of chemotherapy as an arduous treatment. I have no doubt that chemotherapy can be an exceptionally difficult treatment to endure and that for many patients and in certain circumstances it will be a treatment which prevents work. I worry however that a blanket policy reinforces an ignorance about the tolerability of modern chemotherapies and engenders unreasonable fear about cancer treatment. Although I have these concerns I would agree that all chemotherapies will have some side effects but the range of these will vary enormously across a population.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	1	Senior Clinicians	[Redacted]

Posted On: 06/05/2011 14:02:37

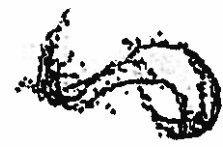
I fully agree with this statement. There are 2 oral chemotherapeutic agents which may be used as monotherapies in the treatment of breast cancer, both are used in secondary breast cancer. They share the same side effect profile as their IV equivalents and other common chemotherapy agents used in the treatment of breast cancer, all of which can be debilitating and occasionally complicated, requiring intervention and monitoring and can affect the individuals physical, psychological and emotional quality of life.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	1	Senior Clinicians	[Redacted]

Posted On: 28/05/2011 09:38:50

I agree with this statement that all forms of chemo are a reasonable proxy for likely debilitation. The role of emerging newer modalities may need separate focussed consideration as drugs are rapidly developed. Standard chemotherapy protocols are debilitating and due to the systemic effects can cause severe side effects for the patient.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	1	Senior Clinicians	[Redacted]



Question: **Chemotherapy** 1 Sub-Question: 1 Group: **Senior Clinicians** [Redacted]

Posted On: 06/05/2011 09:50:29

Patients also respond differently to cancer diagnoses and the psychological effects of cancer and its treatment can often over-ride effects of drug treatment

Question: **Chemotherapy** 1 Sub-Question: 1 Group: **Senior Clinicians** [Redacted]

Posted On: 05/05/2011 21:45:31

I partially agree. Chemotherapy is a spectrum which ranges from very intensive chemotherapy requiring long stays in hospital (e.g. CODe-M for Burkitt lymphoma) and is commonly associated with severe side effects and debilitation, to very gentle chemotherapy given as an outpatient which has little impact on a patient's life (e.g. low dose chlorambucil for low grade non-Hodgkin Lymphoma). The main factor that determines where in the spectrum a chemotherapy regimen lies, however, is NOT route of administration, but what the chemotherapy drugs involved are. For example oral fludarabine and cyclophosphamide is medium strength chemotherapy which frequently leads to more significant debility than cyclophosphamide, vincristine and prednisolone (CVP) chemotherapy which is intravenous.

Question: **Chemotherapy** 1 Sub-Question: 1 Group: **Senior Clinicians** [Redacted]

Posted On: 06/05/2011 17:19:12

I'm finding this really difficult to answer! I'm always conscious of "labelling" people as being eligible for benefits if in actual fact they could be working, as it can be quite destructive to people's psychological ways of coping. However, for people who are receiving oral chemotherapy and do have significant side-effects (or who have impairments relating to their disease), having to go through the stress and trauma of going to a medical is something they really often can't cope with, and I've supported various young people who have not felt psychologically able to go to the medical for ESA (on top of being in and out of hospital for appointments) so have not finished the application process and therefore not been awarded the money. (And then subsequently found themselves in a sticky financial situation because of it).

Many of the oral chemotherapies do have significant side-effects though, and just because they're oral, it doesn't necessarily mean that they should be viewed as the "easy option". I'm not aware of the percentages of people using oral chemo nationally and, of those, how many would be seen as unable to work due to their cancer or the chemo side-effects. I think to make a fair decision, that information would be really useful. But, it would certainly reduce a huge amount of stress and emotional / psychological worry for a lot of people if all chemotherapies were considered to be debilitating. Perhaps there could be some way of reviewing earlier for people having oral chemo? (I've not thought through the implications to that though...!)

Question: **Chemotherapy** 1 Sub-Question: 1 Group: **Senior Clinicians** [Redacted]



Question: **Chemotherapy** 1
Sub-Question: [Redacted]
Group: **Senior Clinicians** [Redacted]
Respondent: [Redacted]

Posted On: 06/05/2011 15 48:58

It is my experience that regardless of route of administration, most patients experience some degree of side effects such as tiredness. It also has to be considered the nature and degree of the patients disease when starting oral chemotherapy, is it being used for curative intent or palliation, this will influence the patients general condition and therefore the impact of any chemotherapy drugs on the patient's general well being

Question: **Chemotherapy** 1
Sub-Question: [Redacted]
Group: **Senior Clinicians** [Redacted]
Respondent: [Redacted]

Posted On: 06/05/2011 17 35:52

The inherent risks to health and wellbeing associated with chemotherapy in all its forms are well documented, and include increased risk of potentially life threatening infections, severe reactions to sudden alterations in environment temperature, exposure to cold and to sunlight. It can compromise skin integrity, balance and proprioception causing significantly increased risks of falls and other accidents.

We advise patients taking chemotherapy to rest, so that they have the optimum chance of a good outcome from their chemotherapy regime, without having to compromise dosages to offset tiredness or infection, caused by stress and lack of time to rest when they feel they have to continue to work to maintain an income and provide for their families and dependants during treatment for a life threatening disease.

I would suggest that Chemotherapy treatment should come with a statutory requirement for the patient to abstain from working, to avoid becoming so debilitated that they end up back in hospital as an unplanned emergency admission.

Question: **Chemotherapy** 2
Sub-Question: [Redacted]
Group: **Senior Clinicians** [Redacted]
Respondent: [Redacted]

Posted On: 05/05/2011 09 00:38

Tiredness and sickness (nausea and/or vomiting) are the most likely side-effects. The risk and severity of these problems varies enormously according to the drug being given and the dose schedule employed. Someone taking oral methotrexate in the maintenance phase of treatment for leukaemia would be likely to have little or nothing in the way of upset whereas someone taking oral capecitabine as part of treatment for bowel or breast cancer might experience considerable distress. Once treatment finishes sickness resolves rapidly, in a few days, but tiredness may persist, and interfere with daily living, for many months and in some cases (usually older people) several years.

Question: **Chemotherapy** 2
Sub-Question: [Redacted]
Group: **Senior Clinicians** [Redacted]
Respondent: [Redacted]

Posted On: 07/05/2011 22:51 35



From a nutritional perspective I would report that the most debilitating side effects of oral chemotherapy are loss of appetite, nausea and fatigue. Some patients may be more likely to experience symptoms with some drugs and it is important to note that some drugs are given at increasing doses to assess tolerance and the highest acceptable dose eg. Glivec. As I do not treat all patients, only those referred with symptoms, I am unable to answer what proportion of patients are affected by this. Typically the symptoms may last for a week or longer after oral chemotherapy although it is important to note that some chemotherapy is given continuously, without a break.

Question: **Chemotherapy** Sub-Question: **2** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 04/05/2011 13:20:11

Sensitivity to cold which make it difficult to go outside & breathe in cold air, hold metal objects, clean teeth and open the fridge. Condition progressive with treatment. This affects about 80% but full recovery is quick once treatment has finished.

Neuropathy in hands that make it difficult to hold small objects such as a pen. Condition progressive with treatment. This affects about 70% but full recovery is usual once treatment has finished.

Fatigue affects all patients and is progressive with treatment, recovery time varies.

Question: **Chemotherapy** Sub-Question: **2** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 05/05/2011 13:38:06

my previous answer was not saved. brief rewrite. fatigue is cumulative worse after cycle 6 than cycle 2. will persist for many months (up to a year in some cases). disrupted eating, sleeping and voiding add to the problems. 10% are pole-axed and 60% severely affected. As many patterns as there are chemotherapy regimens - therefore generalisation is crude.

Question: **Chemotherapy** Sub-Question: **2** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 08/05/2011 00:21:32

The most common debilitating side effect of the oral drugs that I use most is oral capecitabine,

is lack of stamina/ physical fatigue –also the mental fatigue/lack of concentration/lack of mental stamina/difficulty in making decisions. Patients say they “go from full to empty in 20 minutes” and just have to sit down wherever they are.

Nausea or a low grade persistent queasiness also makes it difficult to concentrate.

The hand- foot syndrome makes your hands sore and clumsy so fine movements precision are made very difficult.

Diarrhoea means you want to be near a toilet – sometime in the workplace that simply isn't possible

Taste changes and oral sensitivity tend to make patients eat less and sometimes lose weight



contributing to the weakness/fatigue
 I would say the majority of patients are affected to a degree which although only severe in 20% impacts on daily life in virtually 100%
 Typically these symptoms tend to build up so toxicity accumulates the longer you go on taking the tablets
 The fatigue and mental fatigue may extend for 6-12 months occasionally even longer
 oral etoposide
 hair loss can make patients self conscious and less confident. Nausea is also often a problem
 glivec
 some people tolerate this TKI remarkably well - others have nausea and fatigue.

Apart from the tendency to get worse as treatment continues there is little pattern to toxicity. Things can be fine for 3 course and then toxicity will be severe in some patients.

Question: **Chemotherapy** Sub-Question: **2** Group: **Senior Clinicians** [Redacted]

Posted On: 07/05/2011 22:11:13

The most common oral chemotherapies I prescribe are Capecitabine and Vinorelbine - I use both of these in the treatment of secondary breast cancer and usually my indication for prescribing the drug is that the patient is symptomatic - therefore the patient may already have serious ill-health and debility before starting the therapy.
 The main side effects are diarrhoea, nausea, plantar palmar erythema PPE (this can be severe enough to make walking or using hands painful) and indigestion.
 The majority of patients will not be severely effected (I would estimate less than 20% having severe side effects) and in the majority side effects will be controllable through the use of other medications.
 If a patient were to have severe side effects these would usually be apparent within the first 2-3 weeks of therapy.
 The difficult and sometimes troublesome side effect of PPE can be of long duration and can be debilitating for some patients and be persistent throughout a course of therapy.
 With the biological therapies that we occasionally use the side effects are skin rash and diarrhoea.
 All of these side effects should usually resolve fairly quickly (a few weeks) from the end of chemotherapy

Question: **Chemotherapy** Sub-Question: **2** Group: **Senior Clinicians** [Redacted]

Posted On: 09/05/2011 04:55:18

Listed are the most common debilitating side effects of the 2 oral chemotherapies used in breast cancer, all patients would be expected to experience one or more of these side effects.



DIARRHOEA, NAUSEA & VOMITTING: these side effects may occur and last for a specific number of days during and following each cycle of treatment. However they may also be unpredictable, as may be the efficacy of any treatment intended to minimise the side effects in any one individual. The effects may mean that the individual finds it difficult to leave home for any social/domestic/work related reason, as they need to stay near the appropriate facilities. They may also affect the persons' ability to eat and drink as they would normally.

MUCOSITIS - The effects of mucositis can vary considerably, ranging from mild soreness of the mouth and to extreme break down/ulceration of the mouth and gastric mucosa and severe discomfort/pain. This in turn would impact on the individuals' ability to eat and drink normally and in some circumstances even make it difficult to carry out the basic function of talking.

PALMAR PLANTAR SYNDROME - This side effect is graded 1-3 and ranges from mild tingling, skin redness & dryness of the just the hands, which does not affect the persons ability to perform activities of daily living, to that of severe moist desquamation, ulceration, blistering and pain affecting hands and feet resulting in an inability to walk or perform activities of daily living

FATIGUE - extreme tiredness or exhaustion all or most of the time that will vary from individual to individual but affects around 75% of cancer patients and makes even simple every day tasks difficult to undertake.

Because these treatments are given in the treatment of secondary breast cancer they may be given for as long as the disease remains under control. Time frames for treatment can therefore be vague and unpredictable in addition to the fact that treatment may stop and start at different intervals. Capecitabine in particular can be given for unusually long periods of time and therefore the side effects experienced for prolonged periods.

Question Chemotherapy	Sub-Question 2	Group Senior Clinicians	Respondent [Redacted]
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Posted On 06/05/2011 09:44:17

stomatitis, skin disorders, gastrointestinal symptoms, infection
Variable effects

Question Chemotherapy	Sub-Question 2	Group Senior Clinicians	Respondent [Redacted]
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Posted On 05/05/2011 21:54:11

Side effects:

- Fatigue very common. Debilitating as leads to becoming tired very easily on even fairly minimal work or exercise. Initially often worse 2-3 weeks after the chemotherapy, improving



before the next course. However as the cycles progress the fatigue can become on-going throughout the cycles. Affects probably 40-50% of patients on oral chemo for haematological cancers. Commonly lasts months after the end of treatment. Common regimens causing this are thalidomide and lenalidomide containing regimens for myeloma and fludarabine containing regimens for lymphoma.

- Risk of infection. This can be profound in some regimens such as fludarabine-containing regimens. This can be debilitating as patient are recommended to avoid contact with people with infections and to avoid crowded areas. 50-60% of patients are affected by this and the immune suppression lasts approximately 3-4 months after the end. In 5-10% patients oral chemotherapy can lead to prolonged marrow suppression leading to prolonged infection risk (again, especially with fludarabine-containing regimens).

- Nausea despite antiemetic use. This is usually in the first few days into the cycle. In 5-10% of patients this can be debilitating as constant nausea makes it impossible to concentrate and interact with others in a constructive way.

Question	Sub-Question	Group	Respondent
Chemotherapy	2	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 14:00:29

I don't feel as a social worker I'm best qualified to answer this question! In my experience, the hardest-to-manage side effects of some of the brain tumour oral medications (eg temozolomide or PCV) are the extreme lethargy and some nausea. However, some people who are taking oral chemotherapy for Chronic Myeloid Leukaemia, for example, are able to carry on with their employment fairly easily. Unfortunately, in my experience, it seems to depend which oral chemo someone is having as to how much it would impair their ability to work, which doesn't help in making overall statements about oral chemo.

Question	Sub-Question	Group	Respondent
Chemotherapy	2	Senior Clinicians	[Redacted]

Posted On 06/05/2011 11:59:06

tiredness, fatigue

this can be dependent on the patient's general condition, if they have other co-morbidities and dependent on the intent of the treatment (or the stage of the patients disease)

The duration is hard to predict but the above issues need to be considered in assessing the patient

Question	Sub-Question	Group	Respondent
Chemotherapy	3	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 09:01:55

Again highly dependant on the drug and dose schedule but taken as a global view then probably 75%

Question	Sub-Question	Group	Respondent
Chemotherapy	3	Senior Clinicians	[Redacted]



Question: **Chemotherapy** 3 Sub-Questions: **3** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 07/05/2011 22:32:10

I am not able to answer this as the patients who are referred to me have symptoms / problems with eating.

Question: **Chemotherapy** 3 Sub-Questions: **3** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 04/05/2011 15:09:11

All patients experience side effects to some degree.

Question: **Chemotherapy** 3 Sub-Questions: **3** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 05/05/2011 13:36:56

All patients, to some extent, will experience problems

Question: **Chemotherapy** 3 Sub-Questions: **3** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 08/05/2011 00:24:32

80-90% will experience fatigue to a level which impacts on daily life and for 20% the fatigue is severe. I cant think of any patients who have no side-effects with a course of oral capecitabine lasting longer than 3 months.

Question: **Chemotherapy** 3 Sub-Questions: **3** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 07/05/2011 22:23:25

20-30% to a degree that it was debilitating.
A higher number - maybe 70% to a degree that it was inconvenient

Question: **Chemotherapy** 3 Sub-Questions: **3** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 06/05/2011 09:45:22

Most patients would be expected to have some GIT symptoms and oral inflammation



Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	3	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 21:53:28

I would expect 60-70% of patients with haematological cancers on oral chemotherapy to be affected by one of these side effects.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	3	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 14:01:25

As a Social Worker, I feel this is best left answered by the medical professionals.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	2	Senior Clinicians	[Redacted]

Posted On: 08/05/2011 13:57:08

Since I work in palliative care most of the patients experience side effects such as fatigue

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	4	Senior Clinicians	[Redacted]

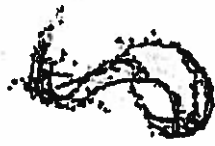
Posted On: 05/05/2011 09:08:08

Oral chemotherapy is likely to be used in one of two ways: either as a relatively short-term treatment (up to 6 months) as part of an adjuvant systemic regimen to or to bring advanced disease into remission, or as a longer-term maintenance therapy. In the latter situation the drugs, and dosages, are such that they usually cause relatively few side-effects and have relatively little impact on daily living, but in the former situation side-effects are more likely as the drugs will often be used at higher dose levels or be more toxic. In other words, someone receiving short-term oral chemotherapy (six months or less) is more likely to experience significant side-effects than someone receiving long-term (six months or longer) treatment.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	4	Senior Clinicians	[Redacted]

Posted On: 07/05/2011 23:36:56

I consider that oral and non-oral chemotherapy can be equally debilitating. Increasingly oral chemotherapy is used in combination with radiotherapy which can also create symptoms. Symptoms can still occur with oral chemotherapy and for some patients they are used



continuously eg. Glivec. It is likely that some drugs create more symptoms than others but this does vary between patients.

Question: Chemotherapy	Sub-Question: 4	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 04/05/2011 13:08:10

Non oral chemo is more debilitating as it is more toxic, however some patient are given oral chemo as they will not manage intravenous and they may experience the side effects as acutely.

This also depend on other factors such as the patient health (other disease that they may have eg diabetes), side effects of radiotherapy, nutrition.

The longer a patient is on treatment the more debilitating they may find it.

Question: Chemotherapy	Sub-Question: 4	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 13:32:14

I see no point (for the underlying biological reasons outlined above) in attempting to discriminate between oral and intravenous chemotherapy in this respect.

Question: Chemotherapy	Sub-Question: 4	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 08/05/2011 00:28:17

Drugs like oxaliplatin are notorious for giving rise to severe fatigue/ mental fatigue/ chemo brain most patients with combinations of capecitabine and oxaliplatin probably score 7 to 8 out of ten in terms of fatigue. With just oral capecitabine this is more like 4 to 5 for out of ten for most patients.

Question: Chemotherapy	Sub-Question: 4	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 07/05/2011 22:28:27

As yet there are no oral chemotherapies licensed for the adjuvant treatment of early breast cancer (ie given to fit healthy women as an 'insurance' form of treatment) so all of these treatments are used in sicker patients with advanced disease and this changes the comparison somewhat.

The oral chemotherapies I use I tend to use precisely because they are less toxic (and convenient) than their IV counterparts. Generally speaking I would consider oral chemotherapies to be less debilitating with the important exception of those patients who get severe PPE (about 5-10%) on Capecitabine



Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	4	Senior Clinicians	[REDACTED]

Posted On: 09/05/2011 08:36:04

I would say that oral and intravenous chemotherapies could certainly be considered to be equally debilitating when used in the treatment of breast cancer. Oral chemotherapy may be seen as 'convenient', however these drugs have the same (common) side effects, only the route of administration is different. Oral treatment may negate the frequency and intensity of hospital visits, but this is not necessarily an advantage or a help to patients coping with such treatment as this may reduce some of their routine contact time/support opportunities with their specialist team which has the potential to impact on their psychological health and ability to function. Additionally for some, being responsible for administering their own treatment can be very challenging.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	4	Senior Clinicians	[REDACTED]

Posted On: 06/05/2011 09:54:48

A difficult question. The effects of treatment with any modality needs to be medically assessed for each individual patient. The drug modalities available also are rapidly evolving so it is not wise to generalise here. My view here is that patients need to be assessed medically and psychologically for an adequate opinion of their degree of debilitation.

Question:	Sub-Question:	Group:	Respondent:
Chemotherapy	4	Senior Clinicians	[REDACTED]

Posted On: 05/05/2011 22:01:07

My opinion is that the key issue is what the actual drug is, what the dose is, and how long it is being given for - not the route of administration. The route of administration is largely irrelevant.

For example, fludauridine can be given as an oral or intravenous preparation. It is equally active orally and consequently associated with equally severe side effects.

Another example is oral chlorambucil. Although in low doses this is extremely well tolerated, in higher doses patients can get mouth ulcers, fatigue and can become very susceptible to infection.

The most extreme example I can think of is oral busulphan which can be given orally in high doses as part of a bone marrow transplant conditioning regimen, which is probably considered to be the strongest chemotherapy which is ever administered to patients!



Question:	Sub-Questions:	Group:	Respondent:
Chemotherapy	4	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 14:12:58

My experience of oral chemotherapy in TYA patients, is mainly relating to people who have brain tumours (Temozolomida or PCV). My feelings would be that they can both cause extreme fatigue, and often some nausea, meaning therefore that it could easily be argued to be equally as debilitating as many IV chemos. However, I also know that other oral chemos (such as for CML as mentioned previously) can have fewer side-effects in those people who I've known taking it (again, I only know for young people). For them, having a short-cut to ESA could, in some few people, encourage them to not look for work or get on with life, when in actual fact they could safely be working. This could either be for the fact that they don't wish to work, but also for some people, it could also give the picture that it's not safe for them to be working, even if that's incorrect. But I am aware that my awareness of oral chemotherapy is fairly specific and limited.

Question:	Sub-Questions:	Group:	Respondent:
Chemotherapy	4	Senior Clinicians	[Redacted]

Posted On: 06/05/2011 13:36:06

In my opinion oral chemotherapy can be just as debilitating as IV chemo due to the following:
 The nature/ extent of the patients disease
 the intant of treatment is is it curative or palliative
 Any existng co-morbidities
 Cumulative affect/ effect of ongoing treatments

Question:	Sub-Questions:	Group:	Respondent:
Radiotherapy	1	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 09:17:08

Radiotherapy is given with either curative or palliative intent. Palliative treatments in general are likely to use low doses of radiation, short courses of treatment, and cause few side effects. For curative treatments debilitation is much more likely as these usually involve prolonged courses of radiotherapy over a number of weeks with high doses. The degree of debilitation is also affected by the site of treatment: radiotherapy to the head and neck will be far more debilitating than radiotherapy to the breast. Overall with curative treatments tiredness is the commonest side effect and about 75% of people will experience fatigue sufficient to interfere with day to day living, and for some people this can persist for many months after treatment. Other side effects, and their impact on daily living, depend on the area being irradiated and vary considerably in their nature and severity. Only a small minority of people undergoing curative radiotherapy would be able to continue work during treatment, and most would need a period of at least one to three months to recover afterwards.

Question:	Sub-Questions:	Group:	Respondent:



Question: **Radiotherapy** | Sub-Question: **1** | Group: **Senior Clinicians** | Respondent: [Redacted]

Posted On: 07/05/2011 22:38:52

I would consider the most debilitating forms of radiotherapy affected the gastrointestinal tract eg. oesophageal, stomach, gastrointestinal and pelvic cancers. This is because they cause symptoms such as dysphagia, nausea and diarrhoea. Radiotherapy can also cause fatigue which is difficult to manage and is very debilitating for patients.

Question: **Radiotherapy** | Sub-Question: **1** | Group: **Senior Clinicians** | Respondent: [Redacted]

Posted On: 04/05/2011 14:28:40

Likely debilitation from Radiotherapy treatment is when it is given in combination with chemotherapy, side effects are normally worse and more pronounced. Most debilitating is Total Body Irradiation, head & neck, colo-rectal and Upper GI treatment. These patients are likely to experience fatigue, eating difficulties, nausea, diarrhoea, thrush, sore skin, reflux and mouth ulcers.

Question: **Radiotherapy** | Sub-Question: **1** | Group: **Senior Clinicians** | Respondent: [Redacted]

Posted On: 05/05/2011 13:41:35

All radiotherapy treatments produce fatigue and its degree is not necessarily related to site of disease or treatment volume. Head and neck treatments and treatments for pelvic cancer are particularly debilitating because of their additional effects upon nutrition, bowel habit and urinary symptoms. A patient with head and neck cancer will typically lose 10% of body weight over a course of treatment - the debilitating effects of this are obvious and are compounded by the fact that it may take several years before a patient regains the weight they have lost.

Question: **Radiotherapy** | Sub-Question: **1** | Group: **Senior Clinicians** | Respondent: [Redacted]

Posted On: 07/05/2011 22:43:42

Radiotherapy (in contrast to chemotherapy) is a targeted treatment and as such its side effects are constrained by the part of the body that is being targeted - by way of example breast radiotherapy is generally well tolerated with minimal side effects - it causes some minor fatigue. Head and Neck radiotherapy by contrast is exceptionally debilitating causing difficulty swallowing, eating and severe pain.

All radiotherapy can cause skin reactions (where the skin may peel and blister) and the degree of this skin reaction varies from person to person based on different genetic factors that have not yet been fully elucidated

Question: **Radiotherapy** | Sub-Question: **1** | Group: **Senior Clinicians** | Respondent: [Redacted]



Question: Radiotherapy Sub-Question: Senior Clinicians [Redacted]

Posted On: 09/05/2011 08:58:29

When used for the treatment of breast cancer, radiotherapy may not be the most debilitating of therapies when compared to its uses in other cancers. I am not sufficiently informed about the use of radiotherapy in a broader sense to allow me to comment as to the most debilitating forms of radiotherapy.

However radiotherapy for Primary breast cancer will vary on the individual; the area treated, the persons' prior state of health and the amount and type of other treatment they have already received and its duration. Variations in severity of side effects are exceptionally individual. Treatment is often delivered following a course of chemotherapy when patients may be still recovering from its short term effects whilst potentially dealing with the long term effects. This situation may then be compounded by undergoing radiotherapy so that a period of time exists where there is a 'cluster' of side effects.

Question: Radiotherapy Sub-Question: 1 Group: Senior Clinicians [Redacted]

Posted On: 05/05/2011 16:19:37

The cumulative effects of RT in the head and neck are debilitating. Dryness of the mouth, taste loss, skin and mucosa changes and damage to teeth and supporting jawbone also. Muscle contraction produces trismus and there can be difficulty in chewing, eating and swallowing

Question: Radiotherapy Sub-Question: 2 Group: Senior Clinicians [Redacted]

Posted On: 05/05/2011 14:23:43

Again, as a Social Worker, I feel it's not really appropriate for me to answer this question, but in my non-medically trained profession, my experience would suggest that those young people having radiotherapy to the brain experience the most debilitating side-effects due to the somnolence / fatigue which often occurs several weeks after the treatment has stopped. Throat / jaw / neck radiotherapy can also cause substantial throat pain / very painful mouths too. But as you say, it varies greatly upon the site and duration of the radiotherapy.



Posted On: 05/05/2011 14:35:33

Another problem with the radiotherapy causing people to be unable to work tends to be related to the distance they need to travel to receive their radiotherapy. Whilst not strictly a "debilitating side-effect of treatment," it is a very legitimate reason for many people as for why they couldn't be working whilst receiving radiotherapy treatment. For someone who has to travel an hour and a half each way plus leaving extra time to find parking once at the hospital, plus the time taken to sit waiting for that days treatment etc., it can, for some, be a huge chunk of the day gone. At our particular hospital, some patients need to travel by bus, ferry and another bus from the [redacted] and this would definitely render them unable to work, but not strictly for reasons of medical, but practical, side-effects of requiring the treatment.

Question Radiotherapy	Sub-Question 2	Group Senior Clinicians	[redacted]
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Posted On: 06/05/2011 14:02:53

head and neck: pelvic floor: full head : radical prostate
these types of radiotherapy can have extensive and long lasting side effects which significantly impact on the patients ability to carry out their activities of daily living
EG
weakness, diarrhoea; nausea, vomiting, fatigue, extremely tiredness

Question Radiotherapy	Sub-Question 1	Group Senior Clinicians	[redacted]
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Posted On: 06/05/2011 17:38:01

patients receiving radiotherapy often talk about how tired they become as the treatment programme continues. This is associated with the stress of actually attending the hospital on a daily basis for several weeks at a time, often, in order to complete the treatment. This tiredness can in turn compromise their general health and wellbeing and increase the risk of secondary infections and side effects associated with the treatment and their ability to cope, generally.

Question Radiotherapy	Sub-Question 2	Group Senior Clinicians	[redacted]
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Posted On: 05/05/2011 09:24:16

Tiredness (fatigue) is the most common and most debilitating side-effect. It will affect 75% or more of people undergoing curative radiotherapy. It varies enormously in severity and can be quite debilitating, individual variation is the big factor here rather than specific treatment sites or schedules, similar people receiving identical treatments can suffer widely different levels of fatigue. Fatigue is more likely, though by no means confined to, older people, and can persist for months if not years after treatment (again the older the person the longer they are likely to take to recover. Other side effects are more site specific and again there is enormous variation in their severity and duration. For example for men undergoing radical radiotherapy for prostate



cancer most will experience diarrhoea during treatment and for a few weeks after, but about 5% will go on to develop chronic radiation proctitis with long-term if not permanent, debilitating bowel problems. So whereas most people having curative radiotherapy will have recovered more or less completely within six months there will be a minority (perhaps up to 5%) who will have chronic, possibly permanent, debility following treatment.

Question Radiotherapy	Sub-Questions 2	Group Senior Clinicians	Respondent [Redacted]
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Posted On: 07/05/2011 22:24:48

Types of radiotherapy that are particularly debilitating are those to the head, neck, oesophagus and stomach. They cause dysphagia, loss of appetite, sore mouth, reduced food intake and malnutrition. For patients in these groups it is likely that all patients will be affected by these symptoms to the point where they will require pain killers and advice regarding their dietary intake. The side effects of treatment would typically last one month or longer. Some patients will not recover the ability to eat and will require long term tube feeding. Fatigue is a common side effect and again may last for weeks or months.

Question Radiotherapy	Sub-Questions 2	Group Senior Clinicians	Respondent [Redacted]
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Posted On: 04/05/2011 16:44:18

Diarrhoea, severity varies for each patient, affects most patients having their pelvis treated, should settle a few weeks post treatment.
 Sore mouth & throat, affects all patients having that are having area treated, severity varies for each patient, should start to settle a few weeks post treatment although resulting weight loss may have longer effects.
 Sore skin, may affect any patient having radiotherapy, severity varies for each patient, should settle a few weeks post treatment although may be a permanent change in colour and texture.
 Fatigue, may affect any patient, severity varies for each patient, recovery time varies for each patient.

Question Radiotherapy	Sub-Questions 2	Group Senior Clinicians	Respondent [Redacted]
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Posted On: 05/05/2011 13:49:47

Debility cumulates during treatment. the burden of travelling every day for treatment for 6 to 8 weeks is a factor but the biological effects of radiation upon dividing cells of normal tissues is the dominant factor. By the end of radical treatment the majority of patients are very tired and those who attempt to work during treatment will usually have given up. As with chemotherapy, the debility can persist for months after the completion of treatment. Side effects will depend upon the area that is treated but can include - mucositis, diarrhoea, anorexia, skin reaction (burns), cystitis, nausea, vomiting, headache, somnolence and so on.



Question: Radiotherapy	Sub-Question: 2	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 08/05/2011 00:37:47

Typically these symptoms from radiotherapy also tend to build up so toxicity accumulates the longer you go on with treatment. The fatigue and mental fatigue may extend for 6-12 months occasionally even longer. If you have recently had major surgery as well prior to radiotherapy, or due surgery after radiotherapy things can be much worse.

Question: Radiotherapy	Sub-Question: 2	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 10/05/2011 07:17:49

Radiotherapy treatment centres are typically located in a single centre within a Cancer Network - these can often be a long distance from a patient's home and an important factor to consider is the travel involved in attending for treatment.

It is not uncommon for me to have patients from Hastings who have to make a 70 mile round trip along a slow coastal road every day for 7 weeks - this would make it impossible for them to work even if they were fit enough to do so.

Radiotherapy to the head and neck and oesophagus causes mucositis (sore mouth and throat) which is painful and prevents normal eating and drinking. As a consequence of this a majority of these patients require morphine based analgesia during treatment and nearly all will require dietary modification and advice (liquid feeds etc). 25% will need some form of tube feeding (A tube placed directly into the stomach) and 10% will be admitted to hospital at some stage during the therapy for support.

Radiotherapy to the bowel or pelvis (including prostate) can cause nausea, bowel upset, bladder instability. Treatment for diarrhoea is often necessary. Hospitalisation is rare.

Radiotherapy to the brain causes total alopecia and often cause extreme sleepiness (somnolence syndrome) although note that this often is at its' worst several weeks after the radiotherapy has finished.

Lung treatment can (ironically) worsen breathlessness due to a temporary inflammation of the lungs (pneumonitis) reaching a peak about 6 weeks after treatment.

There is population variation in the degree of these side effects and we still don't know why some are more severely affected than others - cigarette smoking, obesity, high blood pressure and diabetes all seem to predict for more difficult side effects but the response remains unpredictable.

Typically side effects will reach a peak a few weeks after treatment and then improve on a daily basis such that usually all acute effects of treatment have resolved by 3 months.

Question: Radiotherapy	Sub-Question: 2	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 09/05/2011 09:56:48



In isolation, the most common side effects of radiotherapy for primary breast cancer are its effects on the skin & fatigue.

SKIN/NORMAL TISSUE DAMAGE: Ranging from mild soreness/redness to moist desquamation and break down of tissues.

FATIGUE: (as described above) which may be cumulative throughout the duration of treatment, and potentially lasting for weeks/months following regardless of prior adjuvant treatments.

Both of these side effects can potentially affect the patients ability to carry out activities of daily living and quality of life. The majority of patients will experience these common side effects in varying intensities.

Radiotherapy may also be used in the palliation of symptoms in secondary breast cancer and commonly result in fatigue/increased fatigue at a time when the patient may already be suffering many other problems as a consequence of their disease progress.

Question:	Sub-Question:	Group:	Response:
Radiotherapy	2	Senior Clinicians	[Redacted]

Posted On: 06/05/2011 09:31:27

Mucositis, pain, tasteless during RT and upto 1yr after treatment. The mucositis usually settles post treatment.

The dentition is also at risk as is the jaw bone and effects of RT at a late stage such as jaw necrosis can be severely debilitating.

Dry mouth is the most common complaint and severity of this impairs eating, swallowing and speech. A universal complaint but most patients tolerate a few years into follow up.

Question:	Sub-Question:	Group:	Response:
Radiotherapy	2	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 14:29:14

In my non-medically trained experience, the fatigue / somnolence from radiotherapy to the brain can be especially debilitating, both during, and for several weeks after treatment. This can often occur 4 to 6 weeks after the treatment has ended, which, if someone has had 6 weeks of radiotherapy, is a substantial period of time when they may be unable to work. However, again there are exceptions, and some young people have managed to continue with work / education



around radiotherapy appointments (even for neuro oncology), and only needed a few days a few weeks later for the somnolence.

Question: Radiotherapy	Sub-Question: 2	Group: Senior Clinicians	Respondent: [REDACTED]
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Posted On: 06/05/2011 14:06:06

It's impossible to say which are more debilitating the severity may be dependent on the patients general health and age Also the intent of the treatment, eg patients having full head radiotherapy for brain metastasis will already be unwell prior to the treatment the patients social support network, ability to manage to cook and get food will also determine how they are affected

Question: Radiotherapy	Sub-Question: 2	Group: Senior Clinicians	Respondent: [REDACTED]
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Posted On: 06/05/2011 17:47:36

Bowel cancer patients talk about uncontrolled and unpredictable bowel function, faecal incontinence, diarrhoea and severe excoriation of the skin around the anus and buttocks, or around the site of their stoma, as a result of acute radiation enteritis as a side effect of radiotherapy. This in turn also affects energy levels, their ability to maintain adequate hydration and nutritional status, and increases their risk of general deterioration and infection - especially since the radiation and chemotherapy are often given in combination - especially for rectal cancer patients.

There are no effective treatments for the management of acute radiation enteritis which means that it cannot be risk assessed and managed in the same way as might be possible for patients receiving chemotherapy.

In addition, the burning of the skin and deeper structures, loss of function and sensitivity secondary to nerve of other local structures can also cause difficulties with urinary incontinence and infection.

Burning of the skin is a very common side effect, and given that the lower pelvic area and buttock are affected, this can make any activity that involves sitting intolerably painful, and again, there is no way of preventing this side effect - it can only be managed in terms of palliating symptoms and reducing risk of infection from broken skin until such times as it is able to heal on its own. During this time, depending on the severity of the reaction, it may not be possible to wear any clothing in direct contact with the skin, making it impossible for people to maintain dignity and what would be considered a normal standard of dress for any public environment.

Question: Radiotherapy	Sub-Question: 2	Group: Senior Clinicians	Respondent: [REDACTED]
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Posted On: 05/05/2011 09:38:19



Site of treatment and individual variation are key here. People having curative radiotherapy for head and neck or pelvic cancers are more likely to experience debilitating side-effects, that may well be long-term, than those having breast or chest irradiation. Equally some women having radiotherapy for breast cancer will actually say they found radiotherapy harder to cope with than chemotherapy, although they will be in a minority.

Posted On: 07/05/2011 22:42:08

Radiotherapy is comparable to chemotherapy and in some circumstances may create more symptoms, particularly as the side effects continue for a long period of time. The circumstances may be in patients such as those with head and neck cancer, oesophageal cancer, gastric cancer and some of the pelvic cancers. The side effects can continue for many weeks, even months, and be very debilitating. Some patients will require long term nutritional support in terms of enteral tube feeding after radiotherapy, particularly to the head and neck.

Question	Sub-Question	Group	Respondent
Radiotherapy	3	Senior Clinicians	[Redacted]

Posted On: 04/05/2011 15:51:27

Debilitating effects of radiotherapy are comparable to the effects of chemotherapy depending on the area being treated. Patients having radiotherapy in the Head & neck area or the pelvis could be considered to be dealing with side effects as debilitating as those of chemotherapy. Side effects have been discussed in question above.

Question	Sub-Question	Group	Respondent
Radiotherapy	3	Senior Clinicians	[Redacted]

Posted On: 03/05/2011 13:54:01

once again the system failed to save my answer. briefly: XRT and chemotherapy similarly debilitating (rests on the biological effects on normal tissues); chemoradiation increasingly used - anus, gynaecological cancer, lung cancer, bowel cancer, head and neck cancer, brain tumours therefore it becomes academic to try to separate out the effects of each modality

Question	Sub-Question	Group	Respondent
Radiotherapy	3	Senior Clinicians	[Redacted]

Posted On: 06/05/2011 06:40:02

It is simply not possible to compare the treatments - they lead to very different and very individually different reactions

Question	Sub-Question	Group	Respondent
Radiotherapy	3	Senior Clinicians	[Redacted]



Posted On: 10/05/2011 07:21:00

See answers above.

Certainly I believe that radical (Curative) treatments for cancer with radiotherapy which are usually given over long courses of 20-35 daily treatments can be very debilitating. In our Cancer Centre a radical course of treatment for head and neck cancer is considered the most difficult of any of the treatments we offer.

Palliative treatments by contrast are usually delivered in a very small number of treatment sessions (fractions) and as such are generally better tolerated.

Question: Radiotherapy	Sub-Question: 3	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 09/05/2011 08:57:11

On their own and in general, the short term side effects for radiotherapy for breast cancer are often viewed as being less debilitating than the effects of chemotherapy. However some individuals will suffer severe effects of radiotherapy having had few effects from their chemotherapy. This makes identifying situations/cases where radiotherapy is as/more debilitating than chemotherapy exceptionally difficult to identify.

Question: Radiotherapy	Sub-Question: 3	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 18:25:51

Most of my patients have adjuvant chemotherapy given to enhance the functions of Radiotherapy and surgery for cancer cell death. This is in the form of 2 courses during RT and patients symptoms vary from lassitude to severe toxicity and neutropenia. By 6 months of successful treatment these effects are not considerable but the effects of treatment could be upto 18 months or longer for some

Question: Radiotherapy	Sub-Question: 3	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 06/05/2011 09:35:33

Head and neck cancers are more responsive to Radiotherapy than chemotherapy. Chemo is used as an adjunct and in trials newer therapies are being used also.

When chemo is used for sarcoma of the head and neck the effects are systemic and more debilitating for the patient. The cancer is usually more aggressive and requires surgery in addition.



Question: Radiotherapy	Sub-Questions: 2	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 14:42:39

Again, I'm not the best-qualified person to answer this question, and am only familiar with the most common cancers for 16 to 24 year olds, which tend to be very different from those of the older population. However, I'd say that some radiotherapy is definitely as debilitating as some chemotherapies, as people can experience nausea, extreme fatigue, pain and swelling etc. I don't feel that all people receiving radiotherapy treatment are unable to work though, and it does, very much depend on the type of cancer, co-morbidities, the emotional / psychological state of the patient and their ability to cope with the stress / demands, but also the practical considerations of coming to hospital on a daily basis, including financial and time implications. Even for those who receive radiotherapy to a site where the side-effects are less intense, other considerations need to be taken into account, including emotional state and time taken to travel to actually receive the treatment.

Question: Radiotherapy	Sub-Questions: 3	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 06/05/2011 14:06:42

See the answer above

Question: Radiotherapy	Sub-Questions: 3	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 06/05/2011 17:51:40

I think each element of cancer treatment comes with its own risks and side effects and are dependant upon the individual ability to tolerate treatment and the management and palliation of expected and unexpected side effects and iatrogenic disease. It is often impossible to predict who will experience the most severe side effects and almost all patients I have been in contact with over the years have said that they could not believe how tired this kind of treatment had made them, and how unprepared they were to cope with the effects of the treatment they had received, Irrespective of modality. I would suggest therefore that it is not a case of one being worse than the other, but rather that they are both equally demanding and debilitating in their own right and should be considered as such.

Question: New & Emerging treatments	Sub-Questions: 2	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/09/2011 09:39:25



My personal experience here is limited but in the past I was heavily involved with the development and use of the biological agent interferon. Like other biological therapies this has often been considered less toxic than chemotherapy but this is more a reflection of the facts that it does not have immediate life-threatening toxicity, in the way that cytotoxic drugs do, and does not have the same level of acute (immediate) toxicity. But many people taking interferon for more than a few weeks found it profoundly debilitating and, arguably, more troublesome than many conventional chemotherapy regimens. Once again it comes down to questions about the drug and regimen employed and individual variation.

Question: New & emerging treatments	Sub-Questions: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 07/05/2011 22:42:40

I am not currently seeing patients on new or emerging treatments.

Question: New & emerging treatments	Sub-Questions: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 10:30:21

Cetuximab is a monoclonal antibody that is being used for some Head & neck patients.

There is a skin reaction side effect with this drug that affects all patients and can be so severe that treatment may have to be interrupted until the skin has cleared. Patients experience a full recovery after treatment.

Question: New & emerging treatments	Sub-Questions: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 13:55:46

my experience with imatinib and sunitinib is that the fatigue and muscle pain and flu like symptoms are very bit as debilitating as conventional chemotherapy. The majority (over 70%) will experience significant problems.

Question: New & emerging treatments	Sub-Questions: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 06/05/2011 00:46:47

All the oral tyrosine kinase inhibitors as a class cause fatigue -- although some are recognised to be worse than others. For some it is profound and the patient may attend the clinic in a wheelchair. However, unlike chemo/RT my experience is the symptoms improve rapidly when you stop -- maybe as little as 7 days and patients say they feel well.



Question: New & emerging treatments	Sub-Question: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 10/05/2011 07:28:31

Generalising, the biological treatments tend to be well tolerated and with less side effects. Trastuzumab (Herceptin) for example has little to no side effects with some mild flu like symptoms affecting some patients and most of my patients complaining only of the inconvenience.

Cetuximab can cause mild diarrhoea and an unsightly acne-like skin rash. Lapatinib is not dissimilar to Cetuximab in side effects profile.

Most of these are well tolerated and are not debilitating but do please note that most of these are given in combination with other treatments and as such are adding their small burden of toxicity to an already high burden of toxicity. By way of example the drug cetuximab is often recommended to be added to radiotherapy in the treatment of head and neck cancer. This recommendation was made on the basis of a trial which reported additional benefit to this approach but with no statistically significant differences in toxicity. Although this is true, closer reading of the trial that shows that in 18 of the 23 toxicities reported the patients having the extra treatment were a little bit worse. None of these scales reached statistical significance however in our experience we have found that that additional small burden across a number of different domains (skin, pain, eating etc) makes the treatment as a whole very much more difficult.

Question: New & emerging treatments	Sub-Question: 2	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 09/05/2011 08:58:21

One newer oral biological treatment used in secondary breast cancer – Lapatinib – whilst not widely used has some side effects which may be particularly debilitating that are worth mentioning:

Approx 30% of people have diarrhoea which may be severe

30% Skin changes. Some of which may be severe enough to affect activities of daily living

Fatigue

Question: New & emerging treatments	Sub-Question: 3	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 22:04:59

- Imatinib / dasatinib for chronic myeloid leukaemia. This is generally very well tolerated. Patient can experience ankle swelling, palpitations and mild fatigue initially but generally these symptoms improve with time



- lenalidomide for myeloma. This is more problematic. 30-40% of patients experience significant fatigue. 50-60% of patients experience bone marrow suppression which increases the risk of infection.

Question	Sub-Question	Group	Respondent
New & emerging treatments	1	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 14:43:33

I don't feel qualified to answer this question!

Question	Sub-Question	Group	Respondent
New & emerging treatments	1	Senior Clinicians	[Redacted]

Posted On: 06/05/2011 17:53:15

For Radiofrequency Ablation and Cyberknife treatments, the side effects can manifest as mild symptoms of a flu like illness that pass in a few days, to a full blown syndrome that can take several weeks to recover from.

Question	Sub-Question	Group	Respondent
New & emerging treatments	2	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 09:34:39

As indicated above with some drugs and treatment schedules newer agents can be every bit as debilitating as conventional cytotoxic treatments.

Question	Sub-Question	Group	Respondent
New & emerging treatments	2	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 10:38:24

The side effects of cetuximab are comparable to a severe radiotherapy skin reaction.

Question	Sub-Question	Group	Respondent
New & emerging treatments	2	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 13:34:11

little different

Question	Sub-Question	Group	Respondent
New & emerging treatments	2	Senior Clinicians	[Redacted]

Posted On: 10/05/2011 07:28:33



Tend to be less debilitating but (as above) it is rare that they are delivered as a single modality of treatment and are usually added into existing treatment paradigms.

Question:	Sub-Question:	Group:	Respondent:
New & emerging treatments	2	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 22:05:31

In general they do appear to be better tolerated. However each drug needs to be evaluated on a case by case basis.

Question:	Sub-Question:	Group:	Respondent:
New & emerging treatments	2	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 14:44:13

As above

Question:	Sub-Question:	Group:	Respondent:
Supporting evidence	1	Senior Clinicians	[Redacted]

Posted On: 05/05/2011 16:08:20

The following is list of selected references that I think might be relevant:

Hofman M et al. Cancer-related fatigue: the scale of the problem. *The Oncologist*, 2007; 12 (supplement 1): 4-7. This supplement includes a number of interesting papers on cancer-related fatigue

Stasi R et al. Cancer-related fatigue. *Cancer*, 2003; 98: 1786-1801

Minton O et al. A systematic review and meta-analysis of the pharmacological treatment of cancer-related fatigue. *Journal of the National Cancer Institute*, 2008; 100: 1556-66

Bruera E et al. Challenge of managing cancer-related fatigue. *Journal of Clinical Oncology*, 2010; 28: 3671-3672

Andreyev J. Gastrointestinal complications of pelvic radiotherapy: are they of any importance? *Gut*, 2005; 54: 1051-1054

Denton AS et al. Systematic review of non-surgical interventions for the management of late radiation proctitis. *British Journal of Cancer*, 2002; 87: 134-143

Miller NL et al. Health-related quality of life after prostate brachytherapy. *British Journal of Urology International* 2004; 94:487-491



Fellowfield LJ et al. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. British Medical Journal, 1990; 301: 575-580

Hodgkinson K et al. Long-term survival from gynecologic cancer: psychosocial outcomes, supportive care needs and positive outcomes. Gynecologic Oncology, 2007; 104: 381-389

Meyerowitz BE et al. The psychosocial and emotional fall out of cancer and its treatment. The Cancer Journal, 2008; 14: 410-413

Question: Supporting evidence	Sub-Question: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/05/2011 14:28:03

Chan, C., Richardson, A., & Richardson, J. (2011). Managing symptoms in patients with advanced lung cancer during radiotherapy: results of a psychoeducational randomized controlled trial. Journal of pain and symptom management, 41 (2), 347-57.

Fransson, P. (2010). Fatigue in prostate cancer patients treated with external beam radiotherapy: a prospective 5-year long-term patient-reported evaluation. Journal of cancer research and therapeutics, 6 (4), 516-20.

Kyrdaalen, A., Dahl, A., Hernes, E., Ham, E., & Fosså, S. (2010). Fatigue in prostate cancer survivors treated with definitive radiotherapy and LHRH analogs. The Prostate, 70 (13), 1480-9.

Noel, S., Levy, C., Hardouin, A., Rieux, C., Heutte, N., Séguin, C., et al. (2010, Sep 30). One-Year Longitudinal Study of Fatigue, Cognitive Functions, and Quality of Life After Adjuvant Radiotherapy for Breast Cancer. Int J Radiat Oncol Biol Phys.

Phillips, K., Jim, H., Donovan, K., Pinder-Schenck, M., & Jacobsen, P. (2011, Feb 11). Characteristics and correlates of sleep disturbances in cancer patients. Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer.

Purcell, A., Fleming, J., Burmelster, B., Bennett, S., & Heines, T. (2010, Aug 8). Is education an effective management strategy for reducing cancer-related fatigue? Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer.

Teunk, N., Haffty, B., Chen, S., Khan, A., Nelson, C., Pierce, D., et al. (2011, Mar 1). Comparison of radiation-induced fatigue across 3 different radiotherapeutic methods for early stage breast cancer. Cancer.

Question: Supporting evidence	Sub-Question: 1	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 17/05/2011 07:41:19

Is it only a question of will power? Factors associated with job resumption after primary breast cancer treatment - Stada, Palumbo. POster P2-14-05 at San Antonio Breast cancer Conference 2010

A prospective longitudinal study of over 300 women in a single cancer centre in Italy looking at factors predicting a return to work at 24 months post treatment 32% did not return to work. 73% of these reported that they were 'physically exhausted after illness and treatments'



In multivariate analysis the following were identified:
 Treatment related toxicity 0.64 (0.26-1.54) - not statistically significant
 Disease duration >60 days 2.96 (1.25-7.03)
 Nature of work (physical vs intellectual) intellectual 3.93 (1.57-9.82)

Other factors such as occupational intervention and full time vs part time showed non significant differences.

A similar (but retrospective) American study of >3000 patients was reported at the same conference:

Predictors of employment outcome in breast cancer patients Tevaerweek P2-14-07 SBCS 2010
 They appeared to show that patients who received an increasing number of treatment modalities WERE NOT more likely to suffer a change in employment (factors predictive of change in employment were metastatic disease, black race, Performance status worse than 0 or ongoing therapy)

HAsett et al 2009 and Johnsson et al 2009 have both suggested that chemo recipients were more likely to have change in employment than non chemo recipients

Questions	Sub-Questions	Group	Response
Supporting evidence	2	Senior Clinicians	[REDACTED]

Posted On: 10/05/2011 07:58:56

My personal observation is that whilst many of our therapies have acute toxicity the three biggest obstacles preventing patients being at work are:

1. Fatigue
2. Psychological / Emotional
3. (Fear of) Stigmatisation

Of these three fatigue is the most important and profound in depth and duration. Fatigue is multifactorial but can often be very prolonged after treatment. My experience (and my reading of the literature) lead me to believe that continued work (at some level) help minimise both the impact and duration of fatigue. I frequently encourage patients to have an open discussion with their employers around a flexible working arrangements which allow the patient to maintain some level of (contact with) work throughout treatment. I believe that this is helpful physical and emotionally and speeds rehabilitation at the end of treatment. I worry that more permissive sickness legislation may disincentivise patients from being at work when this can be a helpful thing for them.

Please accept that these are situations which are clearly not universal.

Given the ubiquity of cancer I struggle a little with the concept of it being afforded 'special' status with respect to sickness regulations and as my answers to the prior questions illustrate the diseases and treatments vary so greatly wrt toxicity profiles I find it challenging to generalise. Is there evidence that the current situation makes it particularly difficult for patients? - If so, this is not feedback I have had from my patient group.

finally please accept apologies for any typos - typing is not my forte!



Question: Supporting evidence	Sub-Questions: 2	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 09/05/2011 08:59:00

Bisphosphonates - The bones are the commonest site for metastatic spread of breast cancer. Bisphosphonates are used in those with secondary breast cancer of the bone and therefore this treatment is widely used. The treatment is ongoing until disease progression. There is a strict protocol in taking oral bisphosphonates interfering with the patients start to their day - the drug must be taken a specific length of time before eating, and the patient must remain upright for 60 minutes after taking the drug.

Clinical trials - Clinical trials feature heavily in the treatment of secondary breast cancer. These trials may be demanding, with treatment regimes carrying varying side effect profiles which may be experienced in varying intensities, and with extra hospital visits for follow up and investigations.

Question: Personal profile	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 05/03/2011 08:47:40

I have been a consultant clinical oncologist (radiotherapy & chemotherapy) since 1974. I am now semi-retired doing no clinical work but having an active role in teaching (medical students) [Redacted] in the past my special interests have been breast, bowel and prostate cancer but my present working commitments mean I have to keep up to date with all areas of cancer treatment.

Question: Personal profile	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 04/05/2011 11:10:17

I have been a Therapy Radiographer for 15 years, I have specialised in treating patients who are undergoing bone marrow transplants. In 2009 I became a [Redacted] supporting all patients with informed consent, information and all aspects of patient support and care in the department. In 2010, I started to manage a team of treatment review radiographers and together we form the [Redacted] our patients manage their side effects and other areas of their lives. [Redacted] a cancer diagnosis has had. I have spoken to a [Redacted] before answering the chemotherapy sections.

Question: Personal profile	Group: Senior Clinicians	Respondent: [Redacted]
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Posted On: 15/09/2011 19:17:57



**Colorectal cancer - chemotherapy and radiotherapy
34 years**

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 07/05/2011 23:57:40

I deliver radiotherapy and chemotherapy to patients with gastrointestinal, colorectal cancer and sarcomas. I am interested in the way the elderly cope with treatment. I have been working in this field for 20 years.

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 06/05/2011 15:34:55

I am a Consultant Clinical Oncologist at [Redacted] where I have worked since 2004. I work full time and treat breast and head & neck cancers (and until 2009 lung cancers). I am the Lead Clinician for Head & Neck Cancer [Redacted] am currently leading locally as a pilot site for the [Redacted] on support for Breast cancer patients post treatment.

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 06/05/2011 09:07:15

I am a Clinical Nurse Specialist (Primary Breast Cancer) working for [Redacted] My role is primarily to act as a resource for clients, healthcare professionals and the wider public on the subject of Primary Breast Cancer. [Redacted]

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [Redacted]

Posted On: 06/05/2011 12:00:11

This obviously means I am answering these questions from my specialist knowledge base on Breast Cancer.

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [Redacted]



Posted On: 03/05/2011 16:27:03

I am a Maxillofacial Head and Neck Cancer surgeon working as a Consultant for the last [redacted] but have trained extensively in the management of head and neck cancer.

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [redacted]

Posted On: 06/05/2011 09:13:03

I have been actively involved with [redacted] and work closely with my Cancer Networks and Hospital Trusts to ensure cancer patient pathways work effectively. I am Head and Neck cancer Lead [redacted]

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [redacted]

Posted On: 05/05/2011 21:37:11

I am a consultant haematologist with a special interest in lymphoma and other lymphoproliferative conditions. I work in a teaching hospital 4 days per week, and a district general hospital 1 day per week where I see general haematology patients. I have been a consultant in this area for 9 months but was a specialist registrar in haematology for 4 years.

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [redacted]

Posted On: 05/05/2011 21:47:57

I've been working as [redacted] Social Worker for three and a half years. I work as part of a Multi-disciplinary Teenage & Young Adult Cancer service, providing practical and emotional outreach support to all 16 to 24 yr olds (& the people important to them), diagnosed within the [redacted] I aim to be involved from the point of diagnosis, through to either supporting them into getting back to life after cancer, or being alongside during palliative care, and providing ongoing bereavement support to families after a young person has died.

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [redacted]

Posted On: 05/05/2011 14:48:56

As regards this research, I'm aware that the cancers which are most common in the TYA age range, are not the same as the most common cancers in either childhood, or older adults, so my answers are biased in that respect! However, the patients I'm supporting often don't have



much financial stability or any savings at all to fall back on due to their age, so increasing ease and speed of access to ESA and other benefits is vital!

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [REDACTED]

Posted On: 06/05/2011 13:39:46

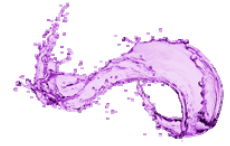
I am a community palliative care clinical nurse specialist in [REDACTED] working in [REDACTED]. I have worked in this team for over 2yrs. I have worked with people with cancer in various specialities since 1985.

Question: **Personal profile** Group: **Senior Clinicians** Respondent: [REDACTED]

Posted On: 06/05/2011 17:28:54

I am a registered general nurse with 25 years experience, and a specialist interest in oncology and palliative care.

[REDACTED]



6.2 Bulletin Board discussion

Section: About this discussion

Question: Welcome

Firstly, thank you for your time and help with the first phase of this research. We really appreciate your contribution and support. We have reviewed all your responses to our initial questions and would now like to get your thoughts on our understanding of those issues and how Macmillan can apply that information in the context of exemptions from the Employment and Support Allowance 'Work Capability Assessment'.

At the top of the screen you will see a number of different buttons:

Navigation - this will let you skip directly to the question you want to answer.

Forward and back arrows - this will let you move through the questions in order

'Unanswered questions' - this will tell you how many questions you have left to answer. But you can ignore "1" as this page is not really a question!!

Under 'navigation' you will see that there are two different 'discussion topics' - chemotherapy and radiotherapy. Under each topic are a number of questions - each of these questions is a new discussion thread. You will be able to reply to the question directly, and also respond to the answers left by other participants.

Over the next few days we would like to work with you all to come up with a proposed wording for the exemption from the 'Work Capability Assessment' that will extend it beyond the current criteria of:

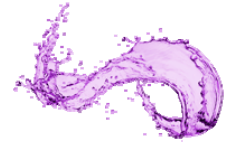
- terminally ill (i.e., their death can reasonably be expected within six months)*
- awaiting, receiving, or recovering from, intravenous, intraperitoneal or intrathecal chemotherapy*

Please bear in mind that any definition Macmillan proposes to the Government must be 'workable' in practice – that is to say:

- that the exemptions should apply to a clear-cut group of patients or under clear circumstances*
- the exemption cannot be based on a list of specific drugs, due to the ever-changing nature of available treatments*

We would really appreciate it if you could make some time to log on to the discussion board every day this week and share your thoughts with each other. Please see this board as a 'conversation' between us all.

Thank you for your time!



Exemption criteria:

Has ongoing debilitating side effects as a result of cancer treatment (surgery, radiotherapy or chemotherapy) resulting in the person being unable to undertake regular work
E.g. Radiation enteritis, psychological trauma post diagnosis, lymphodeama

Posted on 11/05/2011 12:36:27

Section: Chemotherapy

Question: 1.1

Based on the responses we received, our understanding is that:

"The route of administration for chemotherapy (i.e. oral vs. non-oral) is not a good proxy for the level of debilitation that a patient will experience"

Do you agree with this statement? If not, why not?

Yes

Posted on 09/05/2011 18:34:46

I agree. It is the type of drug, the dose and the frequency that are important, NOT the route of administration.

Posted on 09/05/2011 20:01:54

I agree - patients can get side effects from oral medication as they can from non-oral

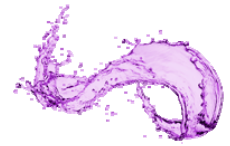
Posted on 10/05/2011 08:21:04

Yes, I agree. It's a combination of drug type, dose, duration but also often co-morbidities etc. too (which is less straight-forward for an overall general statement).

Posted on 10/05/2011 10:34:19

Yes - as above!

Posted on 10/05/2011 12:01:08



I completely agree. It's the drug, dose frequency of administration and side effect profile that are debilitating not it's route of administration.

Posted on 10/05/2011 17:51:40

I agree as the impact/ effect of chemotherapy is dependent on the patient's general well being, the extent of their disease and I also believe the patients individual social, emotional and psychological status and support network impacts on their ability to cope.

Posted on 11/05/2011 12:40:42

I agree.

Posted on 11/05/2011 15:07:58

Thanks for your responses everyone. It looks like there is general agreement on this and it's really useful to get a consensus! If you are new to the discussion after this post, it would be helpful if you could still confirm for us whether or not you agree.

Posted on 11/05/2011 15:32:09

I would agree with the statement and the comments made so far. One point that has not really been mentioned is the huge degree of individual variation with apparently similar people receiving identical treatment experiencing very different level of distress.

Posted on 12/05/2011 07:51:30

I agree

Posted on 12/05/2011 12:25:33

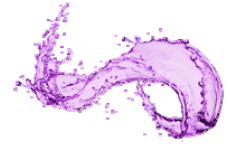
Question: 1.2.

Based on the responses we received, our understanding is that:

"The severity of debilitation experienced as a result of chemotherapy is primarily driven by four main factors:

- The toxicity of the specific chemotherapy drug*
- The length of time that the drug is administered for*
- The dosage*
- The underlying health status of the individual patient"*

Do you agree with this statement? If not, why not?



Yes

Posted on 09/05/2011 18:35:16

Absolutely.

Posted on 09/05/2011 20:02:43

Yes I agree

Posted on 10/05/2011 08:22:07

Agree completely (with the "underlying health status" including emotional / psychological ability to cope too).

Posted on 10/05/2011 10:36:10

Yes.

Posted on 10/05/2011 12:02:54

I agree, and also concur that the underlying health status of the individual patient also includes their psychological health.

Posted on 10/05/2011 17:55:04

I agree to a certain extent as this can be predicted

However I believe that the following aspects can also impact on the severity of side effects;
patients geneal condition, ie co-morbidites

their emotional status

their social support network

their emotional support network

if they live alone or have family/ friends to cook et for them

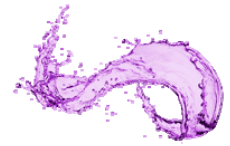
any pressures of family life, ie children, elderly parents to care for, partner/ spouse who needs care, relationship difficulties.

how the person reponnds physically and emoitonally to their disease and the subsequent treatments will often determine how they cope with what may seem to be either major or minor side effects

Posted on 11/05/2011 12:46:39

I agree.

However, the type and form of 'debilitation' will differ from patient to patient as illustatrated by



earlier responses.

Posted on 11/05/2011 15:13:24

Thanks! Again, it looks like we have broad agreement here too. But we're interested the points about a patients emotional status and their social/ emotional support networks. Do others agree that this can have an impact on the severity of the side-effects a patient will experience? In what way?

Posted on 11/05/2011 15:32:50

I would agree that other factors, emotional well being, domestic/financial problems etc can impact on the people's ability to tolerate treatment. Quality of life studies have shown that depression or life events completely unrelated to the individuals cancer or its treatment can impact on their ability to cope with their illness and the side-effects of treatment. I am not sure, however, how one could factor this into the definition we are looking for.

Posted on 12/05/2011 07:58:31

Yes I agree with responses completely.

Posted on 12/05/2011 14:19:28

Yes, I agree. Or at least it can affect someone's ability to cope with the side-effects of the treatment. And how debilitating something is comes down to how an individual can cope with that particular treatment.

Posted on 13/05/2011 15:59:40

I would agree with this statement but would also, as in the previous answer, make the point about the unpredictability of individual responses to treatment.

Posted on 12/05/2011 07:53:45

Yes

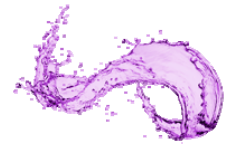
Posted on 12/05/2011 12:25:57

replacing "health status" in the original statement with "health and well-being" might cover these points without becoming too bogged down in detail.

Posted on 12/05/2011 18:30:07

good point - I agree

Posted on 14/05/2011 10:29:41



Question: 1.3.

Given that so many factors influence the severity of debilitation which a patient might experience, we recognise that it is hugely complex and difficult to draw generalisations.

Nonetheless, Macmillan does need to produce a 'universal statement' which could be applied to all patients with a view to ensuring that those who will experience severe debilitation will be exempt from the Work Capability Assessment.

How would you word such an exemption statement? What definition would you use, bearing in mind that it must be 'workable' in practice?

We would like you to provide your own definition and also comment on or adapt those suggested by others.

Any patient receiving treatment for cancer with chemotherapy, radiotherapy, biological therapy or any combination thereof should be exempt from the Work Capability Assessment. This exemption should continue for 6 months after the last dose of treatment.

Posted on 09/05/2011 18:38:30

I do not agree that all cancer treatment should be exempt. For example, people on maintenance rituximab for low grade lymphoma, on imatinib for CML and on low dose chlorambucil usually experience minimal effects from their treatment.

I cannot comment on radiotherapy. With chemotherapy, debility is often associated with degree of myelosuppression. Myelosuppression might therefore act as a useful surrogate for type of drug, dose and frequency. My suggestion is:

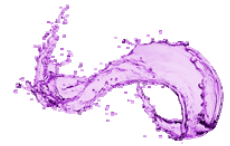
'Any patient receiving courses of chemotherapy and / or immunotherapy which carry a more than 10% risk of febrile neutropenia'

Workability of this definition may be an issue although febrile neutropenia risk is available for most chemotherapy drugs and combinations.

Posted on 09/05/2011 20:15:16

I also wouldn't agree that all treatments should identify someone as exempt, as some oral chemo for CML etc. means someone is still perfectly able to continue with working.

I'd also perhaps suggest that someone could be reviewed just a couple of months after their treatment had finished (with it being flexible though, and easy to respond to, ideally by phone, so



that if their treatment hadn't finished or had taken longer / complications / change of circumstances etc., the review could be delayed). A lot of people are able to continue with work after a relatively short period of time following chemo, and we don't want to discourage that - it's important for a lot of people to "move on" from cancer, and re-engage with life post-treatment, but with the flexibility that some will take longer, and that's fine too...

As for the actual definition, I'm stuck! It can't be down to a list of drugs, we're saying it shouldn't be by how it's administered... neutropenia is a good suggestion, but it can often also be down to the fatigue, but then perhaps people only generally experience that amount of fatigue if it's a stronger chemo? (I'm a Social Worker, so can't really answer that!)

But is it workable for the staff reading ESA forms to know about risks if neutropenia? That again would need changing with new drugs emerging... I'm afraid I'm struggling here!

Posted on 10/05/2011 10:49:53

Are we prevented from referring it back to the treating Physician? I know that I'm potentially giving myself more work here but couldn't the cover-all be:

"Treatment that in the opinion of the treating physician is likely to cause significant debility". If not then any treatment that includes/requires additional supportive therapies might be a workable cover -all, i.e. if anti-emetics and/or GCSF or immodium are needed then it's toxic enough to qualify

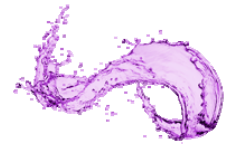
Like others I am somewhat agin the concept of including all chemo as it will be clerly inappropriate for some patients and risks stigmatising chemo patients in the workplace and may delay useful reintroduction to the workplace.

Posted on 10/05/2011 12:13:26

Whilst many patients continue to work through their chemotherapy and radiotherapy, in the breast cancer arena, these treatments in isolation and of course sequentially often bring about the MOST debilitating effects (often clustered) of the treatment modalities used (this includes endocrine and biological therapies too). I am unsure how any other biological therapies are used/side effects of in other tumour groups so I have difficulty commenting on this in a general sense.

So - my suggestion to start with would be:

Any patient receiving treatment for cancer with chemotherapy or radiotherapy as monotherapy or in combination should be exempt from the Work Capability assessment. This automatic exemption should continue for 2 months after the end of these treatments when appropriate assessment can then clarify the persons capability for work at this time. This should take into consideration the individuals physical and psychological recovery and also that



they could be on longer term or maintenance therapies which may or may not impact on their ability to return to work.

Posted on 11/05/2011 10:51:39

I think is very good, but I would suggest 3mths rather than 2

Posted on 11/05/2011 13:06:42

It looks like we have a little more debate on this subject and that one definition is hard to come by. To address some of your comments and queries, I'd just like to explain a little more about how the ESA Work Capability Assessment process works.

In simple terms, what we are talking about is producing a 'tick-list' of criteria that would exempt people from having to undergo a formal assessment of their ability to work. This is done normally over the phone at the point when a person rings up to claim ESA, so needs to be very simple – if a person says they are terminally ill, or they are undergoing IV chemotherapy, they are automatically given the benefit and do not have to through the formal face-to-face medical assessment.

This is, essentially, the pre-assessment stage. All those who meet the list of exemptions will automatically get the benefit but it does not necessarily mean that all other patients will not. Patients who are **not** on the list of exemptions (i.e. all cancer patients not receiving IV chemotherapy or with a DS1500) are then put forward for a physical/ clinical assessment. I'm afraid physician referral at this stage is not an option, but medical assessment does serve at the next stage to 'catch' those who do not get automatic exemption but are too debilitated to work.

It is important to say here as well that this is just about those people who are applying for 'out of work' benefits because they do not feel able to stay in/ return to work. It is not designed to stop those patients who do want to work from doing so.

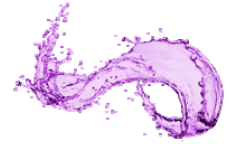
Once the benefit is awarded it automatically applies for a period of recovery as well – the length of this is discretionary.

For these reasons we want to develop an exemption definition that will serve as a good proxy for debilitation – for example "all chemotherapy patients" or "all chemotherapy patients excluding certain categories".

Posted on 11/05/2011 15:36:35

Bearing in mind the above, is "all chemotherapy patients" a good proxy or is it necessary to add a caveat around low grade lymphoma and CML patients (and any others?)?

What would be a workable definition? By this we mean would (the vast majority of) patients be able to self-identify the group into which they fall and would it be easy to provide evidence to



confirm that the patient falls under the exemption criteria?

Posted on 11/05/2011 15:35:47

One possible definition might be to include all people receiving chemotherapy apart from those on long-term (greater than 6 months duration) oral treatments, or to include all people on chemotherapy but build in a review at six months.

Posted on 12/05/2011 08:06:09

I am unable to provide a 'universal statement' and appreciate the attempts made so far.

1. Not all patients will experience toxicity related to treatment.
2. Not all patients should be exempt.
3. Most patients on systemic cytotoxic (or concurrent) treatment should be exempt for 2 to 3 months after the completion of all non-maintenance treatment.
4. Some patients may experience side-effects after the completion of treatment - months or years later (eg. peripheral neuropathy).
5. Are there other non-cancer conditions that are exempt and on what basis? If so, can the definitions/statements be adapted by Macmillan for this exercise?
6. Perhaps patients (as above) should be exempt based on a 'Yes or No' answer which requires no further clarification other than a defined period of time at which point it would be re-assessed. This could be provided by the treating Centre/physician/GP.

Posted on 11/05/2011 15:41:53

Sounds like you could add a 'tick box' for the diagnosis CML which would exclude the patient.

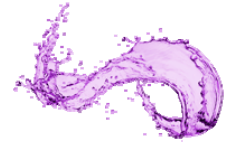
What is the process on the other end of the 'phone line? Does the civil servant filling in the responses do this on a computer? If so would it be that difficult to keep their database up to date with the names of the chemotherapy drugs which we thought likely to cause debility? I accept that this would not be possible on a completely paper based system.

Posted on 11/05/2011 18:09:58

I do not think that all people receiving chemotherapy should be included since (as has already been pointed out) some people on long-term maintenance treatments may have little or no upset and be quite able to work.

Posted on 12/05/2011 08:03:36

It seems that there is general consensus that the vast majority but not all chemotherapy patients should be excluded from the Work Capability Assessment automatically. The caveat appears to be around those patients who are undergoing long-term maintenance treatments. With this in mind,



we'd like to clarify a couple of points:

- a) Do patients know they are undergoing a "long-term maintenance treatment"? For example, would they be able to tick a box on a form to confirm this?
- b) Does "long-term maintenance treatment" capture CML and the low-grade lymphoma mentioned above? Are there any other specific cancer types that should be included in this list?
- c) Does everyone agree with Terry that long-term should be defined as longer than 6 months?
- d) Which would be most workable (assuming that one is broadly a proxy for the other) – "long-term maintenance" or a specific list of cancer types?

Posted on 12/05/2011 11:17:22

I am unsure as to whether all patients would correctly be able to identify themselves as on long term therapy - what they interpret that to be may vary, and you rely on the explanation and their understanding of their treatment schedule/plan. I don't feel able to comment on the CML issue, but I would agree that longer than six months would generally define long term chemotherapy. However there will be those of course who will potentially be on long term therapy as their treatment would be intended to be given until disease progression. This could be seen as maintenance therapy but of course may not be any less debilitating.

Posted on 12/05/2011 14:29:38

It is getting into a bit of semantics but long-term treatment and maintenance therapy could be interpreted as two different things: in the one instance one is continuing treatment because there is a high-risk of relapse if it is stopped (ie CML) in the other its part of a planned programme where the maintenance phase is intended to consolidate previous therapy (ie acute lymphoblastic leukaemia). The difference is subtle but could be a source of confusion if one used one or other definition (long-term or maintenance) and so a simple timescale - such as six months - might be easier. People would generally know if their treatment is intended to continue for six months or more - I think.

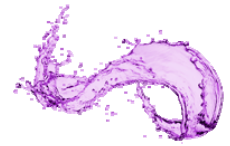
Posted on 12/05/2011 14:43:18

I agree

Posted on 12/05/2011 12:35:56

I think we may need to consider the expression "except for those on continuous therapy of more than six months duration". My original draft was intended to avoid large numbers of patients being summoned for assessment and being subjected to unnecessary stress and harassment. There is nothing to prevent those who wish to work from working.

Posted on 12/05/2011 18:38:03



Thanks for all your further input on this. Based on your comments, the exemption definition that Macmillan is thinking of proposing is as follows:

A patient should be automatically exempt from going through an assessment if they are:

- Awaiting, receiving or recovering from treatment by way of intravenous, intraperitoneal or intrathecal chemotherapy; or
- Awaiting, receiving or recovering from treatment by way of oral chemotherapy except for those on continuous therapy of more than six months duration

Please be assured that while we completely accept that you do not think that method of administration is a valid way of assessing debilitation, we are working with the exemptions definitions that already exist. The first bullet is what already exists in law, the second is what Macmillan would propose is added in.

Would you agree with/ support this definition?

Posted on 13/05/2011 11:35:51

I think that looks plausible (although am a social worker, so not sure completely about all cancer types and treatments!)

Posted on 13/05/2011 16:05:09

Yes - I think so. The logic of the 6 months issue is sound in that we shouldn't be prescribing treatments for longer than 6 months if they are causing debility and therefore (assuming good practice) treatments given for longer than this will be well tolerated.

Posted on 13/05/2011 16:36:38

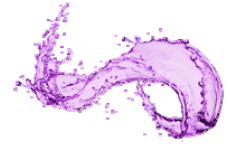
Yes, I think this definition is as specific as it can probably be.

Posted on 14/05/2011 10:34:02

Question: 1.4

Whilst we obviously recognise all the points made so far about the route of administration not being a good proxy for debilitation, it would be useful for us to understand whether there would be any groups of patients receiving IV chemo who would be unlikely to experience severe side effects.

If there are any, please can you specify these?



Not that I can think of within my experience (of TYA cancers)

Posted on 13/05/2011 16:06:57

Important to distinguish between iv chemotherapy and iv biological therapies. Adjuvant breast patients may receive one year of IV Trastuzumab (Herceptin) with little or no side effects.

Posted on 13/05/2011 16:38:04

Perhaps use the expression "IV cytotoxic chemotherapy"

Posted on 13/05/2011 17:30:36

This is an important point - there needs to be clarity that the 2 therapies are different. Apart from the point we keep flagging about individual responses to treatment being different, where one patient might find the FEC bit of a FEC - T regime difficult to tolerate but the taxane easier, and another vice versa (which our service users voice on many occasions) I can't add any other circumstances from my perspective.

Posted on 14/05/2011 10:40:06

I would agree with the comment about the (usual) relative lack of toxicity of some long-term biological/targeted therapies, like Herceptin. The only example of cytotoxic iv therapy I can think of that is usually relatively non-toxic is adjuvant carboplatin in seminoma testis (testicular cancer) which may be as little as a single treatment with little or no side-effects.

Posted on 14/05/2011 09:09:17

Section: Radiotherapy

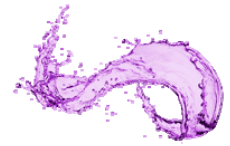
Question: 2.1

Based on the responses we received, our understanding is that:

"Not all radiotherapy treatment is necessarily particularly debilitating but it can be severely debilitating in certain circumstances"

Do you agree with this statement? If not, why not?

I disagree because the majority of radiotherapy treatments are debilitating - only a small minority



of treatments (such as those for skin cancer) can be regarded as causing only minor debility.

Posted on 09/05/2011 18:40:24

I'd agree with this statement (but am aware that as someone who works with 16 - 24 yr olds, it's not representative of the most common cancer types in the majority of people).

For certain tumour-types, it can be very debilitating (eg. brain / throat), and the side-effects can last for a couple fo months afterwards, but for many of the young people who have bone tumours, or some lymphomas, for example, the hardest part of the radiotherapy is the large distance travelled and the commitment to come in every day. They often find the radiotherapy itself much easier than the chemotherapy they've had beforehand, and can be off out to work / education around their radiotherapy.

However, if you think of "debilitating" in terms of the ability to work, it's not easy having to come to hospital 5 days a week for what can take several hours(depending on how far away they live).

Posted on 10/05/2011 10:59:13

Yes - I agree

For many of my breast patients the only obstacle to work during radiotherapy is the travel but for my head and neck patients radiotherapy would be almost impossible.

Posted on 10/05/2011 12:15:06

I would agree with this statement. Many of those having radiotherapy for primary breast cancer do not find it debilitating (although this may be dependant on their prior treatment to date) and manage to work throughout - logistics allowing. However for those undergoing radiotherapy with palliative intent it may not be the treatment but rather their disease progression (and therefore physical and psychological health) which impacts on their capability to work.

Posted on 11/05/2011 14:11:05

I agree.

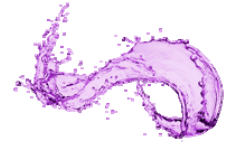
The wider considerations need to be the patients general well being, co-morbidities et

Posted on 11/05/2011 13:09:23

I agree.

Posted on 11/05/2011 15:43:20

Thanks for your responses everyone. It looks like on one level you all agree with this statement, although "certain circumstances" represents more patients for some of you than for others.



If you're new to the discussion, we'd be interested to hear your thoughts!

Posted on 11/05/2011 15:55:24

Yes. Most palliative treatments are short course low dose treatments and relatively well-tolerated and some curative treatments (like routine post-operative radiotherapy following surgery for breast cancer - which accounts for a huge proportion of the people treated) is generally well-tolerated. Equally curative radiation to the head and neck, and pelvis can often cause huge distress.

Posted on 12/05/2011 08:08:31

I agree with this statement.

Posted on 12/05/2011 12:01:21

Question: 2.2

Based on the responses we received, our understanding is that:

"The severity of debilitation experienced as a result of radiotherapy is primarily linked to three main factors:

- The tumour site being treated*
- Whether the radiotherapy is with curative or palliative intent*
- The length of the treatment period"*

Do you agree with this statement? If not, why not?

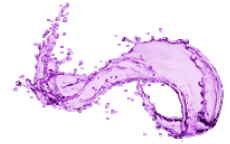
I disagree, a protracted course of palliative treatment will be just as debilitating as a similarly protracted course of radical treatment. It is the fractionation and the dose (as well as the size of the treated volume) that will dictate the debility and we should not be discriminating by treatment intent. Palliative regimens tend to be shorter and simpler and this is why, in general, they may be less debilitating (although the underlying disease may be more debilitating) - in other words treatment intent is not necessarily an independent predictor of the degree of debility.

Posted on 09/05/2011 18:44:20

I disagree. The severity of debilitation may also be influenced by the patient's underlying health status and co-morbidities

I think you would also need to qualify which tumour sites would cause more debilitation - I see this issue has already been raised.

Posted on 10/05/2011 08:25:43



I agree that the intent is linked in with duration and agree that a palliative treatment given over a long period would be debilitating.

Site and fractionation are important

Perhaps the **most** important predictor of toxicity during treatment is whether or not it is delivered with chemo. I cannot think of a Chemoradiation schedule which is not debilitating and would happily agree that all chemoradiation schedules could qualify for exemption.

Posted on 10/05/2011 12:19:14

I agree with the points noted by others that the health status, underlying conditions and if the patient is also receiving chemo need to be considered.

The treatment cannot be considered alone, what else is happening to the patient needs to be looked at to assess their ability to work

Posted on 11/05/2011 13:13:00

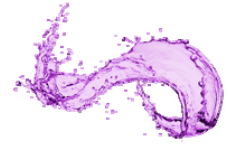
I disagree about the curative / palliative intent clause - obviously if someone has a DS1500 because of their prognosis, this would be irrelevant anyway, but for those having palliative radiotherapy who hopefully have a longer prognosis than 6 months, in my (social work, not medical!) experience, they may still experience debilitating effects. And it may be that they are struggling with other symptoms too. On top of possibly having just been told their cancer is not curable...

I'd probably agree that tumour site is most relevant (taking into account any co-morbidities), but ensuring that it's clear that social / emotional factors and time taken to travel to receive the treatment can all mean someone is unable to work, (or work their normal hours / amount of hours) and shouldn't need to have to argue about it!

Whilst it'd be fantastic for the persons's Consultant to make the decision for each individual, I don't think that'd go down very well as it's an awful lot more paperwork to do on top of already crazily busy workloads! Benefits need to be sorted quickly for people (as often, with the young people I support, they don't have any income at all until their ESA is processed - we can't risk adding another delay into the process).

Posted on 11/05/2011 13:17:18

I disagree. There are far more variables than the 3 factors noted for each individual undergoing treatment as to how debilitating they find their treatment. As my knowledge is very specific to breast cancer I find it difficult to comment on radiotherapy for the different tumour sites but feel



it would be quite difficult to 'rank' debilitation by tumour site.

Radiotherapy can be as debilitating for both those receiving it for either curative or palliative intent, and as already mentioned, whilst palliative regimes may be shorter - the underlying disease at this time may make the treatment all the more difficult to tolerate. So in all circumstances the severity of debilitation may be affected by the patients underlying physical and psychological health as well as any prior or concurrent treatment, and logistical reasons such as travel etc.
Posted on 11/05/2011 14:38:49

No. Although I am not a radiation oncologist, I accept the responses of the other participants.
Posted on 11/05/2011 15:46:04

Thanks everyone! It looks like we got it wrong here with the palliative vs. curative intent so please consider that "removed" from our understanding at the top of this discussion. It also looks like we need to add "the underlying health status of the patient".

With those changes, would you all agree with this statement? (Please note that we've added a new question about combined chemo/radiotherapy schedules later in this section)
Posted on 11/05/2011 15:56:18

Given the changes you have suggested I would agree with the statement
Posted on 12/05/2011 08:12:50

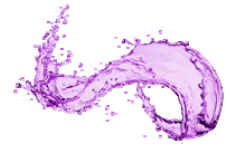
With those changes I would almost agree with the statement, but you would need to take into consideration concurrent treatment (as well as underlying health status - including psychological health).
Posted on 12/05/2011 14:39:14

I also mostly agree about "underlying health status" to include something more general about psychosocial / emotional wellbeing too".
Posted on 13/05/2011 16:10:53

I partially agree with this statement.

Another factor is if the patient is having concurrent chemotherapy (such as Head & Neck patients)

Also as others have mentioned underlying health status, co-morbidities etc.
Posted by on 12/05/2011 12:06:31



I think the revised version will be fine - again the expression "overall health and well-being" might be more inclusive than "health status"
Posted on 12/05/2011 18:41:57

Agree
Posted on 13/05/2011 16:39:44

Agree
Posted on 14/05/2011 10:42:37

Question: 2.3

Based on the understanding that the tumour site is the best proxy for debilitation, Macmillan has proposed the following definition for exemption from the Work Capability Assessment:

"Patients undergoing radiotherapy to treat the following tumour sites should be exempt from the Work Capability Assessment:

- *Head and neck*
- *Gastro-intestinal*
- *Pelvic (including gynaecological, prostate, testicular etc.)*
- *Colorectal"*

Do you agree with this statement? If not, why not?

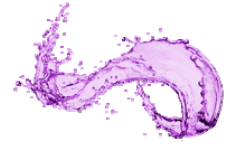
Does this definition need any caveats? If so, what?

I disagree, it misses out Lung cancer. Radiotherapy treatment for breast cancer is also well-recognised as a significant cause of fatigue.
Posted on 09/05/2011 18:45:49

Yes

There may be important omissions - lung and brain.

Whilst I agree that breast radiotherapy is a common cause of fatigue I don't necessarily equate that with debility. I would argue that activity (including work) is the intervention with best evidence to improve it and would not include breast in a standard definition.



Posted on 10/05/2011 12:22:17

I think the definition is good but should include brain and lung radiotherapy as these tend to be debilitating and would prevent the person being fit for work for a significant period of time, if indeed they ever were fit to hold down a full time job dependent on the long term / survivorship outcomes

Posted on 11/05/2011 13:16:11

I'd agree with these categories but am not really qualified to comment on others which may have been omitted (as TYA cancers are different to older persons cancers).

I do think there needs to be something on the form for the decision makers about time taken to receive the therapy though too. If someone is travelling each day, for example, they may well be unable to work for those 6 weeks, despite it being radiotherapy to a "less-debilitating" tumour site. The last thing they need is to then have to fit in a trip to an ESA interview on top of that.

There does need to be the facility for a certain amount of flexibility in deciding for each person - patients need to be able to make their case for why they are unable to work, and for that to be taken into account (whether for emotional or practical reasons). I think staff deciding on ESA claims need to be trained in what is reasonable / unreasonable, and for patients to be told clearly what they need to say when applying, if they feel they have extenuating circumstances (and clearly that would be the case for anyone applying for ESA for any reason, not just cancer).

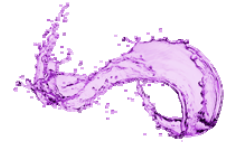
Posted on 11/05/2011 13:26:50

I can't really agree with this statement. Whilst my wider knowledge of treatment of other cancers is limited I agree on the omissions of lung and brain as mentioned by others. I have to state the case for those having radiotherapy for breast cancer which is a common cause of fatigue experienced by many of our clients and service users. They can find their treatment very debilitating when it follows chemotherapy, or a protracted recovery from surgery and so any fatigue already experienced may be compounded. However, whilst the symptoms of fatigue can be helped by activity such as exercise, I don't necessarily include work within the term 'activity' I am afraid. I would stand by my previous answer to Q 2.2, in that there are many variables which will affect debilitating effects of radiotherapy. This means that making any specific caveats extremely difficult.

Posted on 11/05/2011 14:57:29

No, for all the reasons stated by others.

Yes, but again probably too many for a 'universal' definition. The potential prognosis of the



individual patient is also important.
Posted on 11/05/2011 15:51:04

It looks like we missed brain tumours and lung cancer from this list so please consider those added!

Please see question 2.4 for more discussion on an exemption based on tumour site and debate about other cancer types not included in the list here.
Posted on 11/05/2011 15:56:47

I would agree with the inclusion of brain irradiation.

Being pedantic about the above list: radiotherapy for testicular cancer usually involves the para-aortic nodes, not the pevlis, and is usually relatively low dose and well-tolerated, so should this be removed? also colorectal cancer radiotherapy is almost always confined to ractal radiotherapy, which is pevlis irradiation and so does not need a separate category.
Posted on 12/05/2011 08:16:23

Agree with brain and lung being added

Also should include Total Skin Electron Body Treatment for patients having whole body skin treatment. It is very difficult for these patients to work due to the side effects of the treatment.
Posted on 12/05/2011 12:11:41

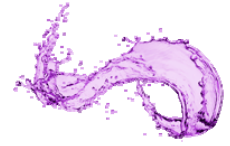
"Abdomino-pelvic" rather than "pelvic" covers the difficulty with testicular cancer, I agree with the comment concerning total body electrons.
Posted on 12/05/2011 18:44:06

Question: 2.4

Would the exemption definition based on tumour sites capture (almost) all patients for whom radiotherapy would be severely debilitating?

If not, what other exemption criteria would you add?

I would not discriminate between tumour sites - all patients undergoing radiotherapy should be exempt from assessment.
Posted on 09/05/2011 18:47:01



Unfortunately not. The psychological and emotional factors mentioned in previous threads impact hugely as do the patient's co-morbidities and the health state related to the disease.

I am once again left thinking that these factors are too varied to fit within a single definition and that physician assessment is the only tool that will capture all of these factors.

Posted on 10/05/2011 12:25:28

I think you cannot make broad statements about site specific treatments without acknowledging the issues on patients general status, emotional, physical and psychological well being support network

I would also agree that patients need to be assessed by a member of the healthcare professional team either doctor, nurse or AHP who is able to consider the whole person and not only the disease or treatment pathway

Posted on 11/05/2011 13:20:42

I don't believe so and in general agree with all the other answers or suggestions up to now (although how 'workable' assessment by the treating physician, specialist hcp or general practitioner would be - is unfortunately questionable).

Posted on 11/05/2011 15:01:49

No. Again it may be easier to include all patients and 'exempt' those who are able to work!

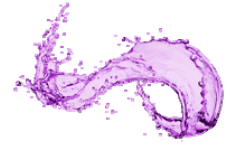
Posted on 11/05/2011 15:54:13

It looks like a definition based on tumour site is tricky here and we'd like to understand a little bit more about how and why, and what could be a workable exemption definition related to radiotherapy.

If you haven't already seen it, please read the explanation under question 1.3 about how the exemption and assessment process works. As a quick reminder, what we are looking for are criteria for exemption – all those meeting the criteria would be exempt from assessment as their condition is considered to be a good proxy for debilitation. Other patients would undergo an assessment and may then be awarded ESA.

Posted on 11/05/2011 15:58:50

Although radiotherapy is upsetting or many people many others tolerate even radical treatments with few problems so i would support a list based on those sites where problems are most likely ie brain, head and neck and pelvic irradiation given that for other sites those people who do suffer



severe problems will still be able to be considered for benefit.

Posted on 12/05/2011 08:20:43

Some of the issues that you have raised are around fatigue (breast cancer) and emotional/ psychological impacts of undergoing radiation treatment.

Would we be right to say that those tumour sites on our (now extended) list at 2.3 cause more severe physical debilitation whilst the debilitation from radiation for other tumour sites is more dependent on the individual's underlying health/ emotional status and social support networks?

Posted on 11/05/2011 15:58:36

Yes, I would agree with this statement, given that where there are exceptions people will still be able to apply for the exemption and are not automatically excluded simply because they do not meet these 'screening' criteria.

Posted on 12/05/2011 08:22:20

I think I can agree with this statement.

Posted on 12/05/2011 14:42:54

Yep, I also agree with the new statement

Posted on 13/05/2011 16:15:09

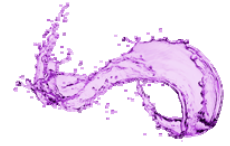
I agree, physician assessment may be the best tool. Some patients continue to work (and want to) during a course of radiotherapy and cope very well. However, for patients who are having a tough time emotionally, psychologically, financially and socially it is not such so easy. Radiotherapy may also be the last treatment after 9 months of surgery and chemo and some patients really start to show the strain at this point.

Posted on 12/05/2011 12:16:58

Question: 2.5

Is the exemption definition based on tumour sites 'workable' in practice?

By this we mean would (the vast majority of) patients be able to self-identify the group into which they fall or would it be easy to provide evidence to confirm that the patient is being treated for one of the exempt tumour sites?



The issue should not be allowed to arise - there should be exemption for all tumour sites. I suspect that - from the government's point of view, it may be cheaper to operate the system in this way. They would probably waste more money than they might potentially save by having to cross-check that patients had accurately stated their tumour site.

Posted on 09/05/2011 18:49:40

I don't believe so.

Take breast cancer as an example

Early breast cancer (EBC) treated with hormones alone - low to no debility

EBC treated with radiotherapy - low to moderate debility dependent on patient factors

EBC treated with chemo - moderate to high debility dependent on patient factors

EBC treated with chemo and then radiotherapy - moderate to high to moderate then low debility as patient passes through treatment phases.

The evidential requirement to demonstrate that the patient was 'within class' would probably be no easier than asking for some form of more individualised certification from the treating unit.

Posted on 10/05/2011 12:30:03

I think patients or their carers are capable of identifying the category they fall into.

However i think organisations such as Macmillan are in the position to help draw up broad guidelines to identify the exemption groups for patients/ carers to follow.

As with DLA or AA the healthcare professional completing or signing the form will take responsibility for supporting the patients claim

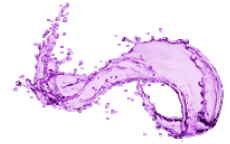
I think the idea of patients being assessed and re-assessed adds to their burden of stress, has huge cost implications and would be unworkable.

Posted on 11/05/2011 13:25:28

I think I agree on this one. An exemption definition based on tumour sites whilst desirable is just not workable in practice.

I am sure that patients would be able to self identify, or the provision of evidence to confirm that the patient is being treated for one of the exemption tumour sites should be reasonably simple. However I don't believe that the sensitivity and specificity of using this method of exemption would really be enough to identify the majority of those who suffer severe debilitating side effects from radiotherapy.

Posted on 11/05/2011 15:49:24



No.

Posted on 11/05/2011 15:55:10

I do not think all people receiving radiotherapy should automatically qualify for exemption and I do think the site-orientated list makes an acceptable, and workable, screening process.

Posted on 12/05/2011 08:24:02

I agree on this one.

For Example a patient receiving 15 fractions of radiotherapy treatment followed by hormone treatment will not have any debilitating effects form this.

I do think that patients would be able to identify the category that they fall in.

Posted on 12/05/2011 12:24:28

I disagree with the statement about 15f and breast cancer. A published a paper in 1996 - mean self-reported fatigue scores doubled from 25% of maximum to 50% of maximum in patients with breast cancer who received 15f of tangential field radiotherapy. There is huge individual variation here and any recommendations we make should allow for this.

Posted on 12/05/2011 18:54:10

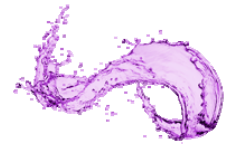
After a rethink - I still believe that exemption by tumour site is difficult, however i do accept that there needs to be a 'line' drawn somewhere.

I would like to point out however that whilst hormone therapy has not been discussed here - point about 15 fractions of rads followed by hormone treatment will not bring about any debilitating effects would be challenged by many of our users!

We speak to many women who (even without going undergoing chemotherapy) struggle with radiotherapy and also with somewhat debilitating subsequent hormone therapy related side effects quite soon after starting treatment - particularly with the AI's; eg joint pain which affects their QOL (a common cause of non compliance). We can say it may not bring about debilitating effects - but we are back down to individual response. However it would be acceptable to me for these people to be excluded from the definition and to undergo assessment of their individual situations.

Posted on 14/05/2011 11:00:21

I think that's a good point. To tell someone that their "radiotherapy's not bad enough" when they



could actually be really struggling could be very detrimental. It may actually be easier to assume exemption for all and hope that staff involved chat to individuals about their capability or not to work (so that they don't think they can't work if they actually could).

Posted on 13/05/2011 16:19:25

Question: 2.6

Based on your comments to the previous questions, we have revised our understanding to the following:

- *Not all radiotherapy patients should automatically be exempt. Radiotherapy patients should only be automatically exempt when:*
 - *They are undergoing a combined chemotherapy and radiotherapy schedule; and/or*
 - *They are being treated for one of the following:*
 - *Head & neck (including brain tumours)*
 - *Lung cancer*
 - *Gastro-intestinal*
 - *Pelvic – gynaecological, rectal, prostate*

This is based on our understanding from your comments that:

- *Those patients undergoing treatment for one of the tumour sites mentioned above are 'more likely than not' to experience severe debilitation. In effect, this means that the criteria serve as a good enough proxy for debilitation that individual assessment is not necessary.*
- *Those patients undergoing treatment for other tumour sites are not 'more likely than not' to experience severe debilitation. In effect this means that whether they are severely debilitated would be best determined through an individual assessment. This assessment would identify those patients who are experiencing severe debilitation, including due to emotional and psychosocial factors.*

a) *Do you agree with this revised definition? If not, why not?*

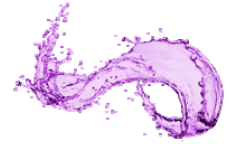
b) *Do you feel this is workable bearing in mind that patients would only need to identify their tumour site and/ or if they are having a combined chemo-radiotherapy schedule? If not, why not?*

A) i would agree with that definition as it would be clear and workable in practice

B)its workable because it allows for patients who do not fall into the exemption automatically to be considered to be eligible as a result of other factors, if the second paragraph" those patients....." is part of the consensus statement

Posted on 12/05/2011 14:33:25

Yes, for the same reasons as noted. The information that has been given clarified the situation a little bit more for me and I can see how difficult this issue is and that there will always be people



who will need to be assessed on an individual basis.

Posted on 12/05/2011 14:52:07

I agree entirely with the spirit of this revised definition but have some (? pedantic) points about the wording:

1. 'combined chemotherapy and radiotherapy schedule' I think it is important to make it clear that this applies when the two treatments are given at the same time (as opposed to a combined schedule that might involve a course of chemotherapy followed at a later date by radiotherapy).

2. The individual criteria are a mix of sites and cancer types and I think this is potentially confusing and should be either on or the other.

I think it is workable.

Posted on 12/05/2011 14:57:49

Yes, in general the statement is acceptable.

Concurrent chemo-irradiation would include those patients receiving combined treatment. Combination would also include those on sequential treatment, usually in the radical setting and therefore likely to be debilitating during the course of the treatment.

Workable - yes with minor adjustments as suggested by others.

Posted on 12/05/2011 15:13:04

I agree with all the points raised and feel that this moving towards a workable soland fair solution

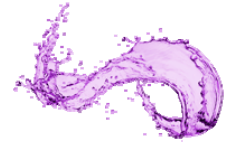
Posted on 12/05/2011 15:25:20

One issue we have not touched on here is the relationship between occupation, debility and fitness to work. A 55 year old cleaner with a BMI of 35 who has had WLE and axillary sampling plus XRT to the breast, SCF and axilla is unlikely to fit for work as soon as her radiotherapy is complete.

Posted on 12/05/2011 18:57:50

That is a very good point and I suppose is down to an individuals situation. It therefore should be taken into consideration when the work based assessment is performed.

However I am concerned about the assessment process for the cohort of people we have been representing here. Having read some of the questions for these assessments, (and talked to many



of our service users), because they are generic, they are not helpful in examining the effects of treatment on QOL and their extent . As a consequence this appears to mean that some are deemed fit to work (and therefore their ESA withdrawn) on the basis of the assessment when they clearly do not feel able to return. Is there any suggestion that the assessment process will be reviewed too?

Posted on 15/05/2011 21:34:50

I think (having not had time to think it through properly!) that this is a workable solution.

Posted on 13/05/2011 16:22:47

Yes I agree with this.

Posted on 13/05/2011 16:44:10

Section: Chemo-radiation schedules

Question: 3.1

Would you agree that all patients undergoing radiotherapy in combination with chemotherapy should be exempt from the ESA Work Capability Assessment? If not, why not?

Yes.

It's rare that this this therapy would not cause compounded side effect profile with moderate to severe debility.

Posted on 11/05/2011 18:02:30

Yes, I agree entirely with comment.

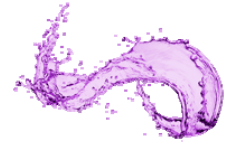
Posted on 11/05/2011 18:28:36

Yes absolutely as the effects of the two therapies together is debilitating for patients to cope with and certainly does impact on their ability to function fully in their daily lives as they did pre-treatment let alone work

Posted on 12/05/2011 07:41:07

Yes, virtually all chem-radiation carries significant toxicity

Posted on 12/05/2011 08:24:54



Yes

Posted on 12/05/2011 12:38:08

Yes

Posted on 12/05/2011 15:13:40

yes

Posted on 12/05/2011 18:58:21

yes

Posted on 13/05/2011 16:23:13

Question: 3.2

Is there any significant difference in the debilitation experienced dependent on whether it is oral or non-oral chemotherapy being administered in combination with the radiotherapy? If so, what?

Yes in terms of side effect profile but not in terms of **overall effect** e.g. Cisplatin with radiotherapy in Head and neck cancer - nausea, severe mucositis, Cetuximab (biological) and RT - skin reaction ++ and mucositis, Capecitabine (oral) and RT - diarrhoea, PPE and mucositis.

Posted on 11/05/2011 18:05:19

I agree with response.

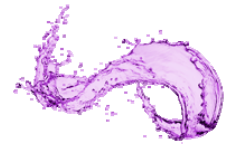
I also think its not approp to begin to classify oral versus non-oral as one being worse than the other. As many others have said in the previous comments the patients well being, support network, emotional, physical and psychological status all have an influence on the impact of the treatment on them

Posted on 12/05/2011 07:43:47

No, I don't believe there is a significant difference in the morbidity between oral and iv chemotherapy in combination with radiation and this distinction should not be made

Posted on 12/05/2011 08:26:40

Agree



Colo-rectal patients have oral chemotherapy and radiotherapy and the overall effect is as debilitating as oral chemo and radiotherapy.
Posted on 12/05/2011 12:43:07

Unless patients receive oral/IV chemotherapy for secondary breast cancer and also have a short course of palliative radiotherapy for symptom control this situation doesn't arise routinely in my specialist area, so I am unable to add further comment on this really.
Posted on 12/05/2011 14:58:55

No.

Again likely to be given either in the neoadjuvant or radical setting, and therefore patients with suffer a degree a toxicity whether oral or iv chemotherapy.
Posted on 12/05/2011 15:16:16

No difference - it is the biological effect that dominates, not the route of administration
Posted on 12/05/2011 18:59:28

I agree with the comments below - delivery method is irrelevant
Posted on 13/05/2011 16:24:10
