THE AGE OLD EXCUSE: THE UNDER TREATMENT OF OLDER CANCER PATIENTS

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Foreword

Time and time again we hear reports of health and social care services failing to give older people the treatment and care they deserve. But what is it like to be an older person going through cancer treatment? Do they get the treatment they should?

The simple fact is that cancer mortality rates in our older population are not improving rapidly enough. If UK mortality rates matched those in the USA, we could prevent around 40 cancer deaths per day in people aged over 75.

It's clear that based on what older people, their families and clinicians are telling us, we must do much more to ensure older cancer patients get the treatment and support that would give them the best chance of beating cancer.

Under treatment is one of a number of factors contributing to the unacceptably poor cancer survival rates among Britain's older population. We know older people are less likely to receive cancer treatments such as surgery, radiotherapy and chemotherapy than younger people. Often, this is medically justifiable – over treatment is just as undesirable as under treatment – but we can't ignore the growing evidence which suggests that many older patients who could benefit from treatment are not being offered it.

Assumptions about someone's ability to tolerate treatment, quality of life or personal preferences should never be based on their chronological age. Two people of the same age may have very different needs and will cope with cancer treatments differently. One 78 year old may be bed-bound, while another may take part in half-marathons. As such, they should be treated as individuals. In spite of this, chronological age is an all too common influencing factor in cancer treatment recommendations.

We must also recognise that the older population is more likely to experience specific issues such as other health problems, social isolation and difficulties getting to and from hospital. Lack of practical support and poor management of non-cancer related health problems present another barrier to cancer treatment.

The issues surrounding under treatment of older people are complex and in some instances contentious. But if we are to reduce cancer mortality rates in the UK, we must begin by admitting that there are thousands of older patients dying unnecessarily from cancer every year. With the number of people diagnosed with cancer set to rise from two to four million in the next twenty years, and with half of cancer cases diagnosed in people over 70, under treatment of this age group is an issue which must be addressed as a matter of urgency.

Ciarán Devane, Chief Executive,
Macmillan Cancer Support

Executive summary

Cancer is a disease of age – half of all new cases of cancer in the UK are in people aged 70 or over[i]. Worryingly, we have some of the worst survival rates in Europe for older people[ii]. Our mortality rates are also higher than the US. More than 14,000 cancer deaths in the UK in the over 75s would be avoided each year if our rates were the same as the USA[iii].

Although late presentation and diagnosis plays a part, there is a growing body of evidence to suggest that older people with cancer are under treated. This may explain why, while mortality rates are improving significantly for the under 75s, they are improving at a much slower rate in those aged 74-84 and actually getting worse for those aged 85 and over[iv].

Macmillan Cancer Support is concerned about a number of issues that may contribute to under treatment:

- Recommendations on treatment are too often being made on the basis of age, regardless of how fit patients may be.
- Assessments do not adequately measure an older person's ability to cope with treatment, and co-existing health problems are often not identified or effectively managed.
- Many patients do not take up treatment because they have inadequate practical support to help them at home, with transport, or with care for dependent spouses and other family.
- Older people are not represented on enough clinical trials, reducing the amount of evidence available to clinicians on benefits and risks of cancer treatment and impact on quality of life.

The solutions

- Older people should be offered treatment based on their fitness, not age, determined by methods of clinical assessment used in geriatric medicine.
- Patients' other health problems and medications should be managed in advance so they are as fit as possible to get the maximum benefit from their cancer treatment.
- Older people and their carers should be provided with understandable information about services which offer practical support during treatment, and helped to use them if needed.

- The NHS Age Equality Practice Guide should be used as a resource to promote age equality within cancer services, and mental capacity training should be more widespread.

- Older people must be included on more clinical trials, and other forms of evidence should be collected to build up a valuable evidence base.

Since 2010, Macmillan Cancer Support has been working with Age UK and the Department of Health to deliver the Improving Cancer Treatment, Assessment and Support for Older People Project, known as the Older People's Pilot. Five pilot sites are testing interventions aimed at reducing under treatment. They will report in December 2012.

The case for action

Cancer is predominantly a disease of age. Half of people newly diagnosed with cancer in the UK are aged over 70. In order to deliver effective cancer care, it is vital that health and social care providers are aware of the specific issues that this age group face.

The UK has some of the worst survival rates in north and west Europe. The relative 5-year survival rates for cancer patients aged 75-99 diagnosed in 1995-99 was 36% for England, 32% for Scotland, 34% for Northern Ireland and 39% for Wales. This compared to 49% for Sweden, 47% for Austria and 45% for Germany. The UK also performed worse than Europe as a whole (40%)[v].

It is estimated that more than 14,000 cancer deaths in the over 75s could be avoided each year in the UK if mortality rates were the same as those in the USA[vi]. These may be partly due to late diagnosis, but there is emerging evidence that under treatment plays a significant part.

The Cancer Reform Strategy in 2008[vii] said there was evidence that older people receive less intensive treatment than younger people even when they are as fit. It clearly stated that age should not be a barrier to treatment.

A year later the All Party Parliamentary Group on Cancer[viii] pointed out that UK mortality rates in the older population are not improving as quickly as in the younger population. From 1995-97 to 2003-05, cancer mortality rates fell by 16-17% for those under 75, but fell by only 6% in the 75-84 age group and actually increased by 2% in the over 85s[ix].

The National Cancer Intelligence Network (NCIN)[x xi xii] has produced a number of reports which show the rates at which surgery and radiotherapy are offered to different age groups. The older the patient, the less likely they are to actually receive the treatment, but it is unknown to what extent the treatment is not appropriate, not being offered, not taken up by the older person or not recorded accurately. Figure 1 shows the variation that exists by cancer and the large fall by age group in the percentage of patients who received a major resection as part of their treatment.

'There's a tendency for one to be less well equipped the older one gets, but that is not true of all people. We all age at differing rates. I know some people of only 45 or 50 who are already 'old', yet others in their 80s or more who are still alert, physically active.'

Peter, aged 85, from Norfolk.

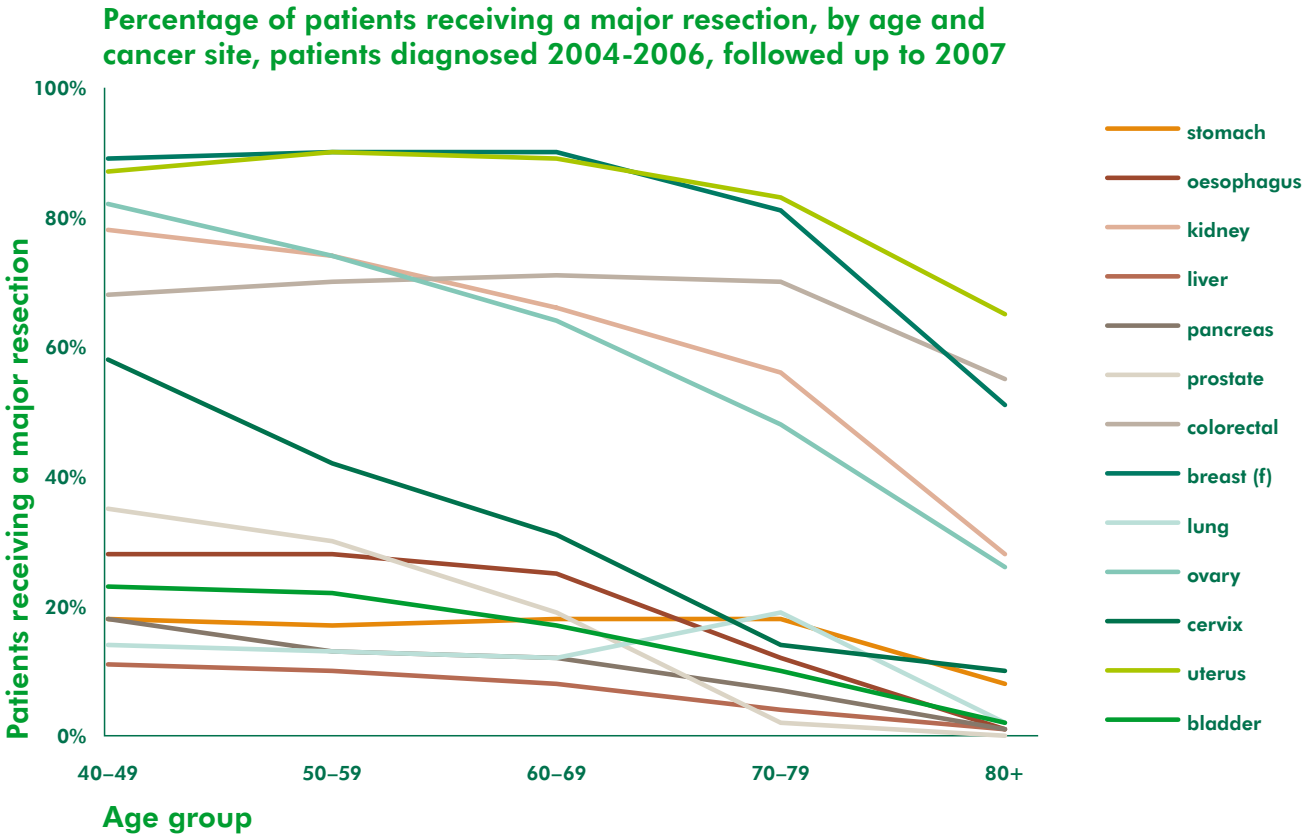

Figure 1: Percentage of patients with a record of a major resection, by age and cancer site, patients diagnosed 2004-2006, followed up to 2007[xiii]

This is pertinent in the context of our ageing population. It is predicted that by 2030, around 17 million people in the UK will be aged over 65, compared to 9.8 million in 2008[xiv]. The number of people living with cancer will double from two to four million in the next twenty years[xv].

People with a diagnosis of cancer should not be written off if they happen to be over 70. Macmillan has begun a 'comprehensive evidence review' to understand the problems and find solutions.

Hazel Brodie, the charity's Older People's Pilot Project Manager, who is conducting the review, says: 'There's growing evidence to show many older people benefit from radiotherapy, chemotherapy and particularly surgery. I'm aware of people in their 80s, 90s, even centenarians having successful cancer treatment nowadays.'

'I'm sure if I was 65 I'd be on a different treatment. I've always been really active; I'm not necessarily a typical 85-year old.'

Interviewee, Walking into the Unknown Report (Macmillan 2010)

Barriers to treatment

Under treatment
When doctors take the Hippocratic Oath, they promise to 'do no harm.' As a result, clinicians are cautious when they give treatment such as chemotherapy, radiotherapy or surgery as they can cause serious side effects; effects more common in the older population.

Clinicians may believe 'over treatment' is worse than under treatment for older people, as it can result in toxicity, infection and death.

One UK study of 101 oncologists found that 81% would prescribe chemotherapy for a high risk breast cancer patient aged 68; however only 47% would recommend the same treatment for an otherwise identical patient aged 73[xvi]. Older people are less likely to have radiotherapy too[xvii].

There is a similar picture regarding surgery. A report by the NCIN showed that breast cancer patients over 70 were much less likely to receive surgery than those under 70. In terms of patients showing symptoms, 85% of the under 70s were given surgery, compared to 54% over that age[xviii].

Breast cancer surgeon Professor Riccardo Audisio believes many surgeons neglect surgery for older patients on the assumption that they respond to hormonal treatment. 'When the cancer comes back two, three, or four years later, you end up regretting not having operated when the woman was much fitter. We have huge evidence of under treatment for these patients.'

Lack of effective assessments
Appearances can be deceptive. Hazel Brodie says: 'The older population is diverse; you could have one 80 year old who is very frail, lots of health problems, unlikely to live another year, but you could also have another 80 year old who has another 20 years of life expectancy. Cancer treatment should be about effectiveness, safety, patient choice, quality of life and never about chronological age.'

Geriatricians acknowledge this and use comprehensive geriatric assessments to examine their patients, which give more information on nutrition problems, cognition, coping with everyday tasks, other health problems and quality of life, in order to recommend appropriate treatment.

These can be time-consuming but it's vital some form of assessment is done within cancer services.

Other illnesses and multi-drug use
Older people are more likely to suffer from other serious conditions such as diabetes or heart disease. Other common health problems in older people include malnutrition, dementia, depression, incontinence and hypertension.

One US study estimates that the average older cancer patient suffers from three co-morbidities[xix]. As a result they will be taking many medicines, known as polypharmacy. One third of the over 70s may have problems with their existing medication regimens at the time they are diagnosed with cancer[xx].

This may be one reason why under treatment occurs; doctors may be very worried about the impact those other health conditions and medications will have on the chemotherapy or surgery.

If these health conditions are not managed effectively, they may reduce a patient's ability to tolerate treatment or cause side effects. This may result in halting therapy and poorer outcomes.

Lack of knowledge of elderly care

Care of the elderly doctors are used to dealing with problems like polypharmacy, falls, incontinence issues, as are GPs – but oncologists and cancer surgeons far less so.

A lack of awareness of how to manage issues commonly observed in older people may contribute to under treatment. In a UK wide survey of 98 oncology trainees, 60% reported that they have never received any training in the particular needs of older people with cancer. A further 19% reported they had received this training only once[xxi].

In orthopaedics or diabetes there is a tradition of the geriatrician being called in to help treat elderly patients, but this appears to be far less common in cancer services. GPs also find that their knowledge of patients is not called on.

Lack of practical support

At any age, cancer can have a substantial effect on a person's independence and it is likely they will need practical help and support due to the disease and its treatment, with, for example, bathing and dressing, transport, domestic chores and caring roles.

Many studies have found a significant difference in levels of support between older and younger people, with older people with cancer receiving less social and practical support. This gets worse as they age, and friends and family die. Many pensioners have low incomes so are less likely to be able to afford to pay for external help[xxii xxiii].

Macmillan Cancer Support is concerned that some older people feel they cannot take up treatment because hospital stays and side effects may prevent them from maintaining normal daily activities, [xxiv]particularly those who are caring for a spouse or other dependent.

Some social services departments do offer some support, but there is no nationwide standard of what assistance older people with cancer should receive. Many healthcare professionals are unsure how or where to arrange certain types of social support.

Age discrimination

The European Social Survey of 2010 showed that Britain is one of the worst in Europe for negative attitudes to elderly people[xxv]. A Help the Aged survey of 200 geriatricians in 2009 suggested that almost half believed that the NHS was 'institutionally ageist'[xxvi xxvii] and were worried about how it would treat them in old age. More than 70% said older people were less likely to be considered and referred on for essential treatments.

The Department of Health's Achieving Age Equality in the NHS Practice Guide was published in 2010 which states in relation to cancer treatment, that 'professional attitudes can be a barrier to older people receiving a full range of treatment options'.

Jagtar Dhanda, Inclusion Programmes Lead at Macmillan says: 'The NHS has a duty of care that extends beyond age categories. To deny treatment based on ill-founded assumptions about age is an unacceptable act of discrimination.'

Jennifer Layburn, Programme Director of the North East London Cancer Network says: 'There is a level of ageism in society whether we like it or not, and everybody recognises it, but we all kind of work as though it doesn't exist.'

The top 5 most commonly diagnosed cancers in men over 75 in the UK are prostate, lung, colorectal, bladder and stomach cancer

The top 5 most commonly diagnosed cancers in women over 75 in the UK are breast, colorectal, lung, pancreatic and ovarian cancer[xxviii]

'It is despicable to neglect, not to offer, not to even go near to the best treatment option only on the simple basis of the patient's age. This has been a horrible mistake that, particularly in the UK, we have suffered from.'

Professor Riccardo Audisio, Consultant Surgical Oncologist.

PATRICIA'S STORY

'I have two dependents - my husband has had two strokes and my son is paralysed from the chest down. People don't understand what a carer is. You go to bed worrying, you wake up worrying and all day you are looking at your watch worrying – who is going to look after them if you are ill. You can imagine me trying to take in a diagnosis of bowel cancer. There was a lot of worry.

'The surgeon was marvellous, he knew about my son and husband and I said I couldn't stay in hospital so he said come back tomorrow and operated on me then. I was out four days later. I did have an information booklet but when you are caring you have very little time to yourself. It's a very busy time.

'You need more support and information for older people on their own than people who have family. I have a terrific husband and a lovely son and I'm fortunate.

'There are symptoms after the surgery, things like incontinence. You think you are the only one with it. You don't discuss it with the doctor and you don't know who to discuss it with.'

'You need more support and information for older people on their own than people who have family.'

Patrica, 75
London

What needs to change

Better assessment methods
Age alone should not be used as a deciding factor on whether to offer cancer treatment. It is crucial to be able to distinguish between patients who appear frail but might actually be able to tolerate aggressive treatment, and separate them from people who may look fit but have other factors which make them less likely to tolerate intensive treatments.

Assessment methods, such as the Comprehensive Geriatric Assessment, can be used to determine how well a patient might tolerate treatment. These assessments are usually carried out pre-operatively, or before and during treatments such as chemotherapy.

The Older People's Pilot Project is testing a variety of assessment methods, including which healthcare professionals are best placed to do them. Geriatricians, cancer services staff and GPs are all taking part.

Joined up working between specialists, primary and social care
Once these assessments have been done, clinicians can arrange specific support for patients to undergo treatment. This could be medical, in terms of the other drugs they are taking, practical in terms of transport to chemo appointments or social in terms of sorting out care for a spouse with dementia during hospital stays.

Overall, good use of geriatric medicine within cancer services should be championed. The International Society for Geriatric Oncology has outlined core principles relating to the care of older patients with cancer, and these should be followed.

Better practical support, and more of it
Some older people may feel they cannot take up treatment because hospital stays and side effects may prevent them from maintaining normal activities[xxix], particularly those who are caring for a spouse or other dependent. Macmillan Cancer Support is testing this assumption through the Older People's Pilots.

Free or affordable short term practical support should be made available from social services and the voluntary sector. This could include providing transport, housekeeping, shopping, care services, dog-walking and even befriending for those going through cancer alone.

Commissioners and NHS Trusts should identify the needs of older people being treated for cancer in their local area, and ensure that there are adequate services. Hospital trusts should produce information booklets and directories which promote and encourage use of this support.

Training for professionals to promote age equality

Age equality training should address age discrimination in cancer services, just like race equality training has in the past. The Achieving Age Equality for the NHS Practice Guide is a good resource which recommends that cancer networks report on inequalities and that local audits are carried out on treatment. Variations should be monitored and reported.

Generally, Age UK recommends that all NHS staff receive training in malnutrition, falls, incontinence, dignity and human rights, care with compassion, safeguarding and neglect and co-morbidities, as well as mental health and dementia[xxx].

Mental Capacity Act training covers issues such as ability to consent and decision-making in patients' best interests when consent is not possible. This is not routinely undertaken by NHS staff and should be made more widely available.

Better evidence

Evidence is required on effectiveness and safety of cancer treatments in older people but this age group is under-represented in clinical trials. This means the drugs are not being trialled in a representative population.

One systematic review reports the median age of colorectal cancer treatment trial participants as 62, which is significantly less than the median age of diagnosis which is 72[xxxi].

Kate Parker, a therapy radiographer at Clatterbridge Centre for Oncology says her experience backs this up: 'Only 5% of clinical trials nationally include patients aged 70 years plus, yet nearly 40% of patients attending CCO are older than 70.'

Most trials have entry criteria which prevent people with certain other illnesses or medications participating – this excludes many older people. These barriers need to be overcome.

On a positive note, eight clinical trials specifically for older cancer patients are underway in the UK. More are needed. Generally, more over-70s should be included in non-age specific cancer trials.

'Let's use tried and tested tools that indicate how frail someone is based on a lot more information, not just their age in years, but their life-years left. This tailored method should be applied to every patient, irrespective of age.'

Kate Parker,
Therapy Radiographer

Case study – Older People's Pilot
'We've had a number of instances where we thought an older patient wasn't coping with their chemotherapy. Geriatricians working with cancer services discovered it was actually other drugs that were causing unpleasant side effects. These were addressed and the patient could continue with chemo. This is a great example of working together to deliver better patient care.' Hazel Brodie

‘We must strive to distinguish what evidence we have and to identify where evidence is lacking. Without doing this, ageism will continue to deprive older people of treatment that they may benefit from and perhaps even worse, give treatments to older people when the evidence suggests that it may not be in their best interest.’

Professor Margot Gosney, Consultant in Geriatric Medicine

Innovation in services

In May 2011, Macmillan began to test new models of care for older people aged 70 and over as part of the Older People's Pilot, in conjunction with Age UK and the Department of Health.

Each of the five pilot sites is testing new methods of assessment for older people with cancer and better ways to coordinate and deliver short term practical support for them during their treatment. They are also looking at promoting age equality in cancer services.

It is hoped that 1,000 patients will be involved. The researchers are due to report at the end of 2012.

Improved communication – South East London Cancer Network
Clinicians at Guy's and St Thomas' NHS Foundation Trust have teamed up with family doctors from 24 GP surgeries in Kent to help assess their older cancer patients.

The GPs use screening tools commonly used by geriatricians, which assess quality of life, as well as psychosocial needs. If the GP picks up undiagnosed dementia, the patient can be referred to a psycho-geriatrician or social services before treatment starts.

The GP sends the results to the oncologist, who uses them to inform the multi-disciplinary team meeting which decides on the way forward for treatment.

Dr Winnie Kwan, one of the GPs from Bexley Care Trust taking part, says: 'Because we know patients better and we're in charge of the rest of their medical condition, we feel there is a role for the GP's to play. We can add information and value.'

- The trust is also providing a practical support directory, full of specific information for older patients with cancer. Where the patient is unable to coordinate their own support because they are too frail or unwell, a nurse specialist helps them do so, so they can continue their treatment.

Better Assessment – Merseyside and Cheshire Cancer Network
Researchers are recruiting 200 patients from St Helens, Knowsley, Clatterbridge and Southport to be risk-assessed before surgery for breast, colorectal or urological cancer.

They are testing three screening tools to see how accurately they predict how well an older patient will cope with cancer surgery:

- The Groningen Frailty Index – 15 questions which cover areas like mobility, vision, nutrition and physical fitness

- VES-13 – 13 questions about ability to perform day to day activities such as shopping, managing money, plus rating their own health compared to others of the same age

- TUG – Timed Up and Go mobility test where a patient is timed, asked to stand from a sitting position, walk 10ft, turn walk back to the chair, then sit again

These tools aim to give surgeons more information about their patients' general health and circumstances, and hopefully will lead to more 'fit' older people being offered cancer surgery.

Consultant surgical oncologist Professor Riccardo Audisio is running the trial. He says: 'The patient is happy to have just 13 or 15 questions and the doctor knows what kind of patient they have in front of them.

'These three tools are yet to be confirmed, but they seem to be promising, they have been tested in cardiothoracic patients and they have proven to be advantageous.'

Involving Geriatricians – North East London Cancer Network

Cancer teams at five acute trusts in north east London are asking elderly care specialists to be involved in the care of their colorectal and breast patients to sort out any issues they may have, so they can cope with the best treatment.

Network programme director Jennifer Layburn believes that in the past, cancer teams may not have asked geriatricians to get involved because they feared they may have told them the patients may not tolerate the full chemotherapy regimen.

In their pilot, she says: 'Geriatricians will deal with the elderly issues, make the patient fit to tolerate the treatment that is best for them.'

Training on attitudes to age – Sussex Cancer Network

Researchers in Sussex are carrying out a survey of attitudes, behaviours and practices regarding older people with cancer amongst the multi-professional clinical teams in three trusts. Subsequently, they are running a series of educational workshops to professional groups, such as GPs.

The training focuses on positive aspects of ageing and how different the ageing process can be for individuals. Older people are playing an active part as 'educators'. At each event, the researchers are evaluating attitudes to age and cancer 'before and after'.

At the end of the project they will repeat the global survey of attitudes, behaviours and practices – with the hope that they will have become more positive about elderly people.

- In Brighton, Age UK has been commissioned to provide volunteer support to patients going through chemotherapy, offering up to two hours a week for tasks such as housework or shopping. They are also phoning the patient, asking if they need financial advice, or signposting to other services. About half of all chemo patients invited are taking up some support.

Peter, 41 and Valerie, 39, 1966

‘There’s a tendency for one to be less well equipped the older one gets, but that is not true of all people’

Peter, 85,
Norfolk

PETER'S STORY

‘I’ve had cancer three times; testicular cancer when I was 45, malignant melanoma at 51, then aged 79 I had surgical treatment for colon cancer.

‘I’m an ex-serviceman and I was in the Fleet Air Arm – the flying arm of the Royal Navy, in World War II and Korea. I had two or three experiences which might be termed ‘narrow squeaks’. As a result, one never becomes immune to the prospect of life being terminated, but you become more capable of handling it.

‘I think the medical profession tends to respond to the individual’s attitude. When I had the colon cancer at 79, I think the doctors felt ‘this individual is bloody minded and determined he’s not going to succumb to this, so if he is pulling his end, we can push our end.’

‘There’s a tendency for one to be less well equipped the older one gets, but that is not true of all people. We all age at differing rates. I know some people of only 45 or 50 who are already ‘old’, yet others in their 80s or more who are still alert, physically active.

‘I have a very active life and still fly as often as I can with chums. In the last few years I have taught my grandson, who is in his 20s, to fly.

‘Cancer is not a death sentence. I’m living life to the full after my third bout. I think the determination and mental stamina you apply is a very considerable influence on survival. I sincerely believe that – whatever your age.’

Conclusion and recommendations

Older people are all individuals with differing levels of frailty, mental attitude and support. Each will tolerate cancer treatment differently.

As the older population grows, and the proportion of them with a cancer diagnosis increases, it is vital that steps are taken to ensure that the right people get the right treatment at the correct level of intensity, together with the practical support to enable them to take up and complete the treatment.

Macmillan Cancer Support recommends:

1 Cancer treatment recommendations and assumptions about elderly patients should not be based on their date of birth. Effective assessments should be used to indicate who will tolerate what treatment.

2 Patients' other health problems and existing medications should be better addressed to ensure they get the maximum benefit from their cancer treatment, ideally with guidance from an elderly care physician.

3 Patients should be provided with information about local services which can offer practical and social support during cancer treatment. An older person should never refuse treatment because they are having difficulties with transport or caring for a relative.

4 The Achieving Age Equality for the NHS Practice Guide should be used as a resource to promote age equality within cancer services.

5 More older people should have the opportunity to enrol on clinical trials; other forms of evidence need to be gathered to build a solid evidence base.

6 As a matter of urgency, more research should be carried out to understand the extent of under treatment and the factors contributing to it.

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We feature real life stories throughout this report.

Cancer is the toughest fight most people will ever face. But they don't have to go through it alone. The Macmillan team is there every step of the way.

We are the nurses, doctors and therapists helping people through treatment. The experts on the end of the phone. The advisers telling people which benefits they're entitled to. The volunteers giving a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.

Our cancer support specialists, benefits advisers and cancer nurses are available to answer any questions people affected by cancer might have through our free Macmillan Support Line on **0808 808 00 00** Monday to Friday, 9am to 8pm.

Alternatively, visit **macmillan.org.uk**
Hard of hearing? Use textphone **0808 808 0121**, or Text Relay.
Non-English speaker? Interpreters available.

WE ARE MACMILLAN. CANCER SUPPORT

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). MAC13040