

Adam: Stoic, pragmatic & independent



*"We all die at some point...
the world doesn't owe me a living"*

People like Adam may be older in age, may be self-reliant and don't like to be a burden to others. They are grateful for the healthcare they receive but are accepting of their prognosis. Because of their age and desire to remain independent, they do not actively seek out help.

Factors that drive decisions and behaviour regarding care and treatment include:

Stoicism	Independence	Resilience	Pragmatism
Maintaining control	Valuing respect	Clear information	

About Adam: Adam is 83 years old. He lives in a rural area in a house on his own. Adam married young when he was in the Army but divorced after 10 years. Although he has no relatives nearby, he has good neighbours that give him lifts to appointments and help with household chores. Before he was diagnosed with mesothelioma, he was fit and well. He enjoyed walking and being in the outdoors. He also takes pride in looking after his appearance, his home and his garden. He likes things spick and span. He attributes this to his time in the forces. Adam was diagnosed with mesothelioma five months ago.

Adam's Military Career: Adam was in the Army for four years. He joined as part of National Service and became an Army medic. He enjoyed his time in the Army. Because he did not serve in the Forces for very long, he does not see himself as a military veteran. However,

his time in the Army has shaped some of his attitudes and how he lives his life. When in the Army, he served in the UK, at a number of different bases. He did not see military combat or conflict whilst in the Army. Neither did he work abroad.

He was exposed to asbestos during his work in the Army. He recalls sweeping up asbestos dust whilst working as an Army medic in military hospitals and living in military accommodation. It took Adam some time to realise that sweeping up asbestos dust was a source of exposure. This was because he believed that only Naval veterans who had worked directly with asbestos were at risk from asbestos-related diseases.

*"You can tell who has
been in the military,
that pride. Even the
guys on the street"*

Adam's Mesothelioma Journey

A friend noticed that Adam was short of breath whilst they were out socially. Adam ignored this for some time. However, he found it increasingly more difficult to breathe and his friends encouraged him to go and see the GP.



His GP wanted to refer him for an X-ray. Adam initially refused because he did not want to cause any fuss and wanted to keep his life on an even keel. In addition, if the X-ray showed that something was wrong, Adam was adamant that he would not take up active treatment.

"If it meant chemotherapy where you get all these side effects, and this, that and the other, I don't really want to know"

Eventually, he did have an X-ray after further pressure from his friends and his GP. After further tests, he was diagnosed with mesothelioma two months later. Adam discussed his diagnosis and treatment options with a nurse specialist. He was keen not to complicate life and keep it as it was for as long as possible. As a result, Adam declined chemotherapy and clinical trials, saying "Well...something's got to kill me".



After some months, he started to experience recurrent pleural effusions, which disrupted his life. He found these distressing because of the shortness of breath and loss of independence. After talking to his nurse specialist and consultant, he did agree to have an indwelling pleural catheter inserted. He has this drained regularly by his district nurse. The IPC has helped him to maintain his independence and keep active in his own home. His breathing is improved and he has reduced discomfort. He only needs to take occasional pain relief.

He doesn't dwell on his illness day to day but just likes to get on with life. As long as he can keep independent, he is happy.



Adam's Compensation Claim

“...there is a scheme apparently to which I said, well I'm not particularly bothered...”

At diagnosis, the clinical nurse specialist asked Adam if she could complete a DS1500 (the special rules form) on his behalf. Adam was told that this form would “confirm his diagnosis” and help him to make a claim for compensation through the Armed Forces Compensation Scheme. At this time, Adam refused to have the form completed because he did not want a fuss. He did not want to claim compensation either because of his age and modest needs.

A few weeks later, he agreed to see advisors from an Asbestos Support Group and Veterans UK. The advisors explained that he could use the compensation to fund care as his mesothelioma got worse. As his health deteriorated, any money from compensation would help to maintain his independence. He therefore agreed to seek compensation through the Armed Forces Scheme. He thought that this money would give him more control over his life.



His claim was initially refused. This may have been because the DS1500 had not been completed and submitted. With the support of his advisors, he appealed against the decision and his Specialist Nurse helped to get the DS1500 completed. The appeal was successful but he found the process difficult and the tribunal distressing. He worried how people would cope with the system if they were experiencing more symptoms than him.

What is the best way to help people like Adam?

Provide clear information that is direct and honest.

Recognise that Adam may change his mind over time and so maintain ongoing contact.

Respect his desire to stay independent and find ways to achieve this.

Work in partnership with other organisations so that Adam has access to the right expertise at the right time, for example a mesothelioma nurse specialist regarding treatment options.

Present information about his treatment and services in a way that makes it clear what the benefit is to him.

Ensure that Adam is seen by an expert to review his occupational history, for example a specialist solicitor or an experienced Asbestos Support Group Advisor. This will mean his risk of asbestos exposure is accurately assessed and not reliant on myths and assumptions.

Be aware that Adam has no family nearby so may lack social support.

Make sure that a DS1500 is completed as soon as possible so that an application to the Armed Forces Compensation Scheme is speedy and successful.

Key messages if supporting someone with mesothelioma who has a military background

- Provide information in a clear and direct way
- Make sure an expert with appropriate experience is involved in occupational history taking and assessing potential asbestos exposure
- Check that people don't have inappropriate or inaccurate knowledge about asbestos exposure based on myths and stories e.g. asbestos was only a problem in the navy
- Make sure that the DS1500 is completed as soon as possible
- Always ask if people have served in the Armed Forces as part of patient or client assessment. Make sure this is documented in the relevant notes
- When discussing seeking compensation, highlight that this can be used to maintain their independence
- Discuss local veteran organisations that may be able to offer support

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Bob & Jill

Both are resilient
and avoid emotions



*"Outwardly he's perfect.
You wouldn't know anything
was wrong with him"*

- Jill

Bob and Jill take pride in being physically and emotionally resilient. Couples like Bob and Jill have been together for many decades. They both come from families who have a military background and the military culture is a big part of who they are. Both Bob and Jill's fathers were in the Royal Navy. Jill is used to being self-reliant whilst her husband was serving abroad. She is used to holding the fort at home.

They are grateful for the healthcare that they receive but rely heavily on military groups for support as they feel that they "speak the same language".

Factors that drive decisions and behaviour regarding care and treatment include:



About Bob & Jill: Bob is 67 and Jill is 60. They have been married for 25 years. They live together in a rural area. They have two grown up sons. One son lives in a neighbouring village with his family and the other lives about two hours drive away. Bob was retired but lives a very active life. He enjoys running and playing golf. Bob and Jill have separate hobbies but attend a local veteran groups together. Jill worked as a teacher but retired once Bob was diagnosed with mesothelioma. They look after their grandchildren on a Saturday. Bob was diagnosed five months ago.

Bob's Military Career: Bob was in the Royal Navy for 42 years. During that time, he travelled all over the world. He was extensively exposed to asbestos when working on ships. He knows others who served on the same ships as him who have developed mesothelioma and other asbestos-related diseases.

During his time in the Royal Navy, he was involved in conflict in the Falklands. Bob does not like to talk about the time when he was in combat. Jill understands this and feels that veterans should not be forced to discuss their emotions and experiences until they want to do so.

While Bob was serving abroad, Jill was at home for several months at a time. She feels that this experience has made her resilient. This means that she is better able to deal with mesothelioma than people who have not spent long periods without their spouse.

"The way that they dealt with everything was to [have a good fight] on the ship on the way back. Whereas nowadays...they go into decompression and they're forced to talk about it, which I really don't believe in."

- Jill

Bob & Jill's Mesothelioma Journey

Bob started experiencing shortness of breath and muscular chest pain in January. He thought that this may be a pulled muscle and kept running through it. After three months, he did make an appointment with his GP when the breathlessness got worse.



There was then a six-week wait for a GP appointment. By the time he attended the GP surgery, he was experiencing severe shortness of breath. The GP immediately sent him to the local hospital after listening to his chest. They drained seven litres of fluid from his lungs on the same day. They also did a biopsy. Bob was diagnosed with mesothelioma with just a consultant present.

"The consultant was too direct and didn't have a good bedside manner"

- Jill



Since diagnosis, Bob's mesothelioma has shown no growth. However, the consultant told them that while Bob's mesothelioma was currently stable, it could "blow up at any time". Both Bob and Jill were very upset by this as they want to focus on the positive. Bob was quiet for a few days after that appointment.

Unfortunately, Bob's latest scan showed slight growth. Bob was quite upset to hear this, but Jill thought it was not in his best interests to dwell on it. She considers it her role to protect Bob emotionally and does not want any "negativity" around him.



Bob and Jill have told their sons about Bob's mesothelioma diagnosis but no other members of their family and friends. Jill does not want sympathy. She is worried that if people start treating Bob as a patient, this will impact negatively on his mental attitude and his general health.

Bob currently experiences some shortness of breath and he gets tired in the evenings. He is no longer able to run or play a full round of golf, but does keep as active as possible. Other than that, he and Jill are focussing on living their lives as normally as possible, for as long as possible.

Bob and Jill do not attend any asbestos support groups as they find it depressing to see people experiencing symptoms. They do continue to attend social groups organised for, and run by veterans.

Bob & Jill's Compensation Claim

Jill came across information about the Armed Forces Compensation Scheme on the internet. She also remembered hearing about compensation from others in the veterans social groups. They were encouraged by this to get advice about claiming compensation as part of the military scheme. Bob and Jill initially sought help and advice from a local asbestos support group advisor. A Veterans UK advisor also came to visit and helped complete the claims form. They opted for the lump sum, Bob wanted to pay off their mortgage and ensure future financial security for his wife.

Both Bob and Jill are happy and impressed with the speed and amount received by the Armed Forces compensation scheme.

When the advisors were completing an occupational history. There was discussion about the source of Bob's exposure. Bob found it hard to revisit the time that he was in combat. However, Bob did not show that he was upset as he tends to avoid talking about emotions. After the visit, he was quiet for a long time.

"I remember thinking it's good he's got me here to mop it up afterwards...she [the advisor] obviously had to say where do you think you got mesothelioma from, so that did open the wound [of Bob's warzone experience] again."



- Jill

What is the best way to help people like Bob & Jill?

Care is required when discussing the source of exposure in the military as it may be linked to a distressing time for example, when in combat.

Recognise their preference to be supported by veteran organisations. Make them aware of veteran organisations of which they may not know.

Be aware that Bob's physical fitness is important to both Bob and Jill and may impact on their relationship. Challenges to the idea of Bob's physical fitness may have a negative impact, and require support and advice.

Recognise that Bob may not show his emotions but his mesothelioma may still have a psychological impact. Careful assessment of his psychological needs may be required.

Jill may also require support as Bob's emotional support system/gatekeeper. However, Jill may not ask for help, even when she needs it.

Helping them both pro-actively plan for future adjustment, in a timely manner, may enable them to feel more in control.

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John:

Values respect, has loyalty to the military, takes pride in physical fitness and puts family first.



"I was quite fit actually... compared to a lot of people, I was very fit"

John is determined to fight mesothelioma with all of the resources that he has, physically, emotionally and financially.

People like John may take pride in their service history and connection to the British Armed Forces. Because of their service in the Armed Forces, they are grateful for any payments or help they receive from military organisations. However, they may simultaneously feel that additional financial support would be beneficial to their care.



Factors that drive decisions and behaviour regarding care and treatment include:

Values financial security for his family	
Pride in physical fitness and strength	Likes to be treated with respect
Pride in resilience	Loyalty to the Armed Forces

About John: John is 65 years old. He lives with his wife Karen in an urban area. John has been married for 24 years. His two sons keep in touch regularly but don't live locally, although they do have a close network of friends. He is very active and enjoys running, swimming and golf. Before he was diagnosed with mesothelioma, he was a plumber. He retired soon after diagnosis. John was diagnosed with mesothelioma two years ago. John and his wife attend local support groups. They also receive support from veteran and civilian friends.

John's Military Career: John was a soldier in the Army for 10 years. During that time, he saw combat in Northern Ireland. He worked in Cyprus, USA, Kenya and Germany extensively whilst employed by the Army and thoroughly enjoyed his time in the military. He very much sees himself as a veteran and is proud of his service. He feels that his time in the military made him mentally resilient and so better able to cope with living with mesothelioma.

John suspects that he was exposed to asbestos when living and working in "bombed out" buildings in Northern Ireland. He doesn't like to talk about this time as it brings back memories of difficult times related to the violence and hostility he encountered. However, when he speaks about his time in the Army more generally, he is very proud of his service. He says he had a great time and met people who have been friends for life. Before leaving the Army, John took a resettlement course in plumbing. He recalls removing asbestos from pipes as part of his training.

John's Mesothelioma Journey



John was previously fit and well, and this was something in which he took pride.

He first noticed that he was out of breath when climbing the stairs at a client's home; when working as a plumber. His wife made him an appointment with the GP who sent him for a CT scan which was inconclusive.

After a biopsy, John was diagnosed with mesothelioma. The news was delivered in a direct fashion, which John appreciated. John was upset about his diagnosis but not completely surprised as he had been asked about asbestos exposure at several points prior to his diagnosis. He also knew colleagues from the Army and plumbing who had been diagnosed with asbestos-related diseases.



"I just came home and thought 'oh well, it's got me'. I was resigned to it"



At diagnosis, John wanted to do all that he could to take action and feel in control. He was also worried about his family and their financial security. He therefore decided that he wanted chemotherapy as soon as possible. John was also clear that he was very willing to try any treatment or trial.

John felt that he dealt with chemotherapy very well and that this was in part due to his level of fitness. Unfortunately, after a while, his chemotherapy stopped working. He was given information about a number of clinical trials that he may be able to enter. However, John did not like the possibility of receiving a placebo. His health care team then considered a drug that was not currently funded by the NHS as part of standard treatment.



He decided to pay for the non-NHS funded treatment using his Armed Forces compensation. He had three rounds of treatment at a cost of £7000 each. The cost meant that they did not go on holiday or do any repairs to the house as they were concerned that they would need their compensation to pay for immunotherapy. They felt that their lives were on hold.

John's First Compensation Claim

"...the most important thing is the treatment is working, and then the second most important thing is how do we pay for it?"

With the help of a local Asbestos Support Group and Veterans UK advisor, John applied for the Armed Forces Compensation Scheme and was awarded a lump sum of £140,000. John was pleased at the speed of the application process and how quickly he received his compensation. However, from speaking to others living with mesothelioma at support groups, he found that payment for his non-NHS funded treatment is frequently included in civil claims but not military claims. He has immense respect for the Armed Forces and thoroughly enjoyed his time serving in the military. However, John felt that the difference between civilian and military compensation schemes was unfair.

"Paying for immunotherapy, that's my biggest worry at the moment. The money isn't coming in but it's going out in spade loads, so that £140,000 will only last us so long"

John's Second Compensation Claim

After speaking to an Asbestos Support Group professional who explained that he may have had dual exposure – that is he had been exposed to asbestos as a civilian as well as during the military service, John realised that he could make a civil compensation claim as well, even though he had been awarded his Armed Forces lump sum. He was advised that he had a good case as a civilian as he could have been exposed to asbestos when working as a plumber. He was employed by a big firm which has been involved in similar claims.

John made a claim with the support of his specialist solicitor and was successful. The amount awarded by the Armed Forces Compensation Scheme was deducted. Although the amount awarded in the civil case was not significantly more than that which was awarded from the Armed Forces scheme, it was still worth pursuing as it included additional payment for any appropriate non-NHS funded treatment.

What is the best way to help people like John?

Provide direct and honest information about treatment and trials.

Provide expert and specialist advice regarding his occupational assessment and the possibility of dual exposure.

Explore local veteran organisations (e.g. breakfast clubs) as a source of support for John.

Speak to John with respect and be respectful about the Armed Forces.

Take care when discussing his experiences of conflict during the military as this may bring up painful memories. This may impact on a patient's mental health.

Be aware that physical fitness is important to his identity so take care when discussing his diagnosis, any deterioration in his condition or his performance scores.

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SUPPORTING OUR

ARMED
FORCES

Zoe: Patient-focused, conscientious and caring

*“As nurses, we want to provide
the best care and support for
our patients”*



Zoe is proud to work in the NHS and is dedicated to supporting patients and their families. She considers it a privilege to care for people in their 'hour of need' and works hard to ensure that each patient receives holistic and compassionate care.

About Zoe: Zoe is an experienced nurse with a palliative care background who has worked as a Lung Cancer Nurse Specialist for the last eight years. Each year, she cares for between two and five patients with mesothelioma. Zoe keeps in touch with current mesothelioma evidence and practice through meetings with colleagues and attending conferences. The area of the UK where Zoe works does not have a history of military service. If one of her mesothelioma patients had a military background, she would not feel confident about how to advise and support them.

Tom: Emotionally reserved and protective of his family

Tom is 70 years old and lives alone in a suburb with good links to the nearest city. Tom's daughter, Sarah, lives close by with her husband and two teenage children. Although Tom enjoys seeing his family regularly, he likes to be as independent as possible and avoids asking Sarah for help.



Tom served in the RAF for 24 years. He retired as an Air Commodore. He served his country all over the world. Tom feels extremely loyal to the RAF. He doesn't want to 'make a fuss' about his diagnosis, feels fortunate to have lived a good life and considers himself lucky to have lived longer than some of his fellow servicemen who died in combat. He enjoys getting together with old friends from his years in the RAF.

Tom was exposed to asbestos when working in an aircraft hanger that was being refurbished. He can recall blowing dust off his notebooks. Two months ago, Tom developed a persistent cough. He went to his GP who referred him for a chest scan. Following the results of his chest scan and a later biopsy, the consultant diagnosed mesothelioma. Zoe was present at the consultation where Tom was informed of his diagnosis.

Five ways that Zoe can support Tom through his mesothelioma journey

Following his diagnosis, Zoe provided a point of contact throughout Tom's mesothelioma journey, spending time with him to explain the diagnosis and provide support and advice at every stage. Zoe recognised how supporting Tom was in some ways different to supporting a mesothelioma patient without an Armed Forces background. Some of the issues that Zoe and Tom faced are described below.

1. Building rapport and trust

Zoe didn't know much about the Armed Forces and was not familiar with military culture. Therefore she did not initially pick up on the fact that Tom had a military background and that this was a big influence on his life. As a result, it was hard for Tom to trust and confide in Zoe. He found it difficult to open up about his service background and how he felt about his diagnosis. Because of this, Zoe found Tom was reserved and closed off to her. The difficulties in building rapport meant that Zoe did not learn about Tom's service background and exposure as early as she would have liked to, in order to give Tom relevant support.

2. Wanting to 'fight it'



Tom's stoical and proactive approach to life was reflected in the way that he dealt with his diagnosis. He was eager to enter clinical trials and explore treatment options. Zoe made sure that she provided information and support about treatments and trials to enable Tom to make an informed decision, recognising that these decisions may change over time.



Sadly, Tom's health declined rapidly and unexpectedly. He was no longer eligible to take part in clinical trials. He was uncomfortable and in pain. Zoe wanted to help Tom but when she broached the topic of palliative care, he shook his head and said that wasn't for him because he "wasn't a quitter". The next time they met, Zoe approached this differently, in a more pragmatic way. She explained how the palliative care team could help him to manage the pain better and keep his independence. He therefore agreed to be referred to receive palliative care.

"I said, 'look, you've got a problem with this pain, it's not easy to control, you need expertise from the palliative care team alongside your treatment'. He accepted this explanation because I'd given it context."



3. Claiming Compensation

After learning of Tom's service background, Zoe was unsure about the next steps with regard to claiming compensation. The benefits advisor attached to her lung cancer services was not sure how Armed Forces service altered potential entitlements. She contacted the Mesothelioma UK helpline. Following their advice, Zoe referred Tom to Veterans UK and the local Asbestos Support Group (ASG) simultaneously.

"Veterans feel very loyal. The 'Military' isn't just any former employer, they've been given accommodation and the opportunity to see the whole world. It's almost like you're suing your regiment, your squadron, your ship and that means the people in those organisations. It feels disloyal."

Zoe sensed his reluctance to claim but explained that if she referred him to the ASG, they would explore his options with him. She explained that this involves more than claiming compensation. He would also get advice on which benefits he is eligible for, and that these could improve his quality of life over the coming months. For example, having a blue badge to ease the stress of hospital parking.

4. Emotional Distress & Mental Health

Zoe did not initially recognise the toll of Tom's diagnosis and that it had triggered emotional distress. He seemed irritable, on edge, described being unable to sleep and experiencing flashbacks. Tom was reliving traumatic events from his time in service when he had lost fellow servicemen and friends in combat. Zoe put Tom in touch with Help for Heroes and Combat Stress. These organisations have experience supporting veterans with mental health issues.

5. Support

Zoe encouraged Tom to involve his daughter Sarah in his care. However, Tom felt strongly about protecting her as much as possible from his diagnosis. Zoe reached out to Mesothelioma UK who provided information about Armed Forces and Veterans Breakfast Clubs, and other military support groups. Tom was comfortable receiving support from people who shared his Armed Forces background. He also wanted to help others at these groups in any way that he can.

"Patients like Tom are looking out for whoever else they can link up with. This fits with a service background where it's 'all for one and one for all!' To have this can-do attitude towards everything; tasks, missions, they just adapt to their current crisis."

What has Zoe learned from her experience helping Tom?

To be aware that a mesothelioma diagnosis may trigger emotional distress for patients with a service background and that they need to be provided with appropriate support.

The importance of completing the DS1500 form as soon as it is appropriate to support the Armed Forces Compensation Scheme claim.

The importance of partnership working and liaising with other organisations involved in supporting mesothelioma patients with a military background. If Zoe had not contacted the ASG, she would not have realised the significance of gathering evidence in a timely manner.

Where can Zoe find more help to support Tom?

- Other patients with a military background
- Combat Stress
- Patient stories from [Mesothelioma UK](#)
- Veterans UK
- Armed Forces & Veteran Breakfast Clubs
- Asbestos Support Groups
- [Help for Heroes](#)

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