

Summary

- It can be difficult to talk to people with life-limiting conditions about their financial futures.
- However, these conversations are vital because of medical advances and inheritance issues.
- While funds can have conversations about this subject, it is still difficult to assess how medicine will evolve over decades.

Mark Ward was 14 years old when a nurse told him and his family that he was HIV-positive. He had been born with severe haemophilia A, a medical condition in which the blood does not clot correctly, and would, as a result, spend years in and out of UK hospitals after slight injuries would lead him into near-fatal conditions. It was through this, from 1977, that he took the now-notorious Factor VIII product, which forms the backbone of the recent ‘tainted blood’ scandal.

One injury as a child led to the deterioration of his left knee, which necessitated an operation in 1983. After six weeks in the hospital, as Ward and his parents were leaving, one of the nurses called across the room, “Mr and Mrs Ward, do you want to know the HIV results? They’re positive. See you next time.”

A follow-up appointment a week later saw the family being informed to not tell anyone of the infection and that Ward should only expect to live for another two to three years and that he should not plan on having an 18th birthday party.

Somehow, he survived. He left school and joined British Airways, but had to hide his HIV status, even when his health eventually began to deteriorate.

“The years before I started getting ill,” he tells *Pensions Age*, “I was earning £26,000. That was decent money back then. Then BA was told I had AIDS, so they wanted to get rid of me through medical retirement or being fired the

Retirement saving and life-limiting conditions

Saving for a pension may seem of less importance to those with life-limiting conditions. But that does not mean that the industry can or should do nothing



next time I got sick. So, I took the retirement and opted for the maximum lump sum, which was only about £14,000 or £15,000. I was dying, so I wanted to leave something to my parents.”

Since then, the treatment of HIV has moved from being a death sentence to something closer to a manageable condition. In 1991, the US’s Centers for Disease Control and Prevention said that the median survival time of those diagnosed with HIV was just 18 months. Now, a single pill lets many lead normal lives.

For Ward, being infected with HIV has tainted his entire life. After leaving BA, he oscillated between working

and periods of ill health. He never saved for a pension. He now spends his time as an activist and will release his autobiography, *Bleeding Fabulous*, later this year. But he remains in a financially parlous state.

“I’m 55,” he tells *Pensions Age*, “and my monthly pension is just over £600 a month. That’s not something you can live on.”

Shifting conditions

Medical science shifts constantly, with conditions and illnesses becoming more manageable over time, and with prognoses constantly adjusted. A terminal, continual decline three decades

ago can now be slowed, extending life expectancy, or even halted. Recent years have seen great strides not just with HIV, but also conditions such as Parkinson's, Multiple Sclerosis, and Alzheimer's.

This is a challenge for the pensions industry: How can you help someone plan and budget for a future they may not believe they will have?

"Having a life-limiting condition can obviously mean quite a broad range of things," says AJ Bell head of retirement policy, Tom Selby, "from terminal cancer and having weeks to live to a more-minor condition that reduces average life expectancy but with the possibility someone might live into their 80s or beyond. And there is always the unknown of scientific breakthroughs that change the likelihood of people with certain conditions living to a ripe old age."

Such things are hard to know or make sense of, which is why proper advice and education is key. It is an argument often made across the financial services sector.

"The biggest thing for me," says WTW director in the DC consultancy team, Gemma Burrows, "is around education and understanding. One thing that we don't do well at as an industry is giving people accessible guidance and advice that will help them make informed decisions. That's something we need to look at, but the flipside to it is that it's often not valued as there's a cost to the advice being given."

The challenge, says Burrows, is that there is an inherent difficulty in getting people to plan for a future they think will not happen. Income may also be a challenge as life-limiting health conditions may mean that income over a career may remain uneven and limited by the struggles of building a career while having medical limitations.

"It is," she admits, "a perfect storm."

Inheritance planning

One aspect that the industry could push on when talking to people with life-

limiting conditions about their future financial health is that of inheritance planning – what will happen to a partner or spouse in the future, and their own financial wellbeing.

"One of the things to remember about pensions," says Selby, "is they are extremely tax efficient on death and can be passed on completely tax-free to your nominated beneficiaries if you die before 75. You can also access your pension flexibility from age 55 (rising to age 57 in 2028), so provided you live to this age then you will be able to access your pot flexibly, with a quarter tax-free and the rest taxed the same way as income."

"How can you help someone plan and budget for a future they may not believe they will have?"

It is a point taken up by Hargreaves Lansdown head of retirement, Helen Morrissey. She points to the 'significant' piece of mind that comes from someone knowing their pension savings will support a loved one during difficult times.

She adds: "With this in mind, it is really important that schemes remind members of the importance of updating paperwork such as expression-of-wish forms to make sure the right people benefit should the worst happen."

There are other aspects that may be beneficial. Those with life-limiting illnesses, says Selby, are likely to qualify for an enhanced annuity, meaning a higher guaranteed income over a shorter period if the insurer anticipates someone having a shorter lifespan. This is a point that could easily be made to those in this situation.

And it is a point that was made in parliament last May. Back then, MP Dave Doogan of Angus asked whether the House would consider early access to

pensions for those with a terminal illness. Doogan's comments were aimed at the UK's state pension, but MP Margaret Ferrier, an independent representing Rutherglen and Hamilton West, said that terminal cancer patients had been told by pension providers that they were ineligible to access their pension earlier as they might live longer.

The landscape for this, however, is varied, with different approaches taken by different pensions providers. The current guidance provided by the government is that you may be able to take your whole pension as a tax-free lump sum if you are under the age of 75 and have a life expectancy of less than a year, provided that certain criteria are met.

Endgame

The situation is not impossible for those in Ward's position, coming into the twilight of their careers with little or nothing saved for retirement.

"Having too small a pension pot isn't something anyone else can do anything about," says Selby. "It is still possible to make up for lost time, particularly if you have a decent salary, if you don't start until your 40s or even 50s, although clearly you'll need to make big contributions."

Burrows echoes this statement. "It's never too late to save," she says. "There are a lot of tax efficiencies around saving, plus there's auto-enrolment."

As to whether pension funds can build in thinking about medical advances, Burrows said that that was a role for underwriters.

"They do consider things like mortality rates and postcodes for how it impacts on life expectancy," she says, "so there has to be some consideration for that sort of thing. But how do you qualify, and to what extent, how something may advance over a certain period?"

 **Written by Pete Carvill, a freelance journalist**