Huntington's Disease Association

Huntington's disease

Advice on life assurance, pensions and mortgages etc.

The impact of Huntington's disease on your financial future

When a person discovers they are at risk to Huntington's disease they may have some financial questions:

- Will I still be able get a mortgage in the future?
- What about my existing life assurance, will it cover me?
- Will I be able to obtain additional life Assurance?
- If I am forced to give up work prematurely, are the benefits provided by my employer secure?
- If I am forced to give up work through illness, what income will I receive and can any shortfall be covered through assurance?
- What will happen to my assets, my house and savings if I am in need of residential care, and how can I protect them?

Some of your questions can be answered here, but there are also many issues which need to be looked at in the context of your personal and financial circumstances and therefore require a confidential personal discussion.

How life assurance products can help

Changes in people's expectations and the level of state assistance mean that we all need to reconsider how we protect ourselves and our families from the financial consequences of possible misfortunes.

All this adds up to the fact that everybody – particularly if they have a young family – should take action to provide some form of safety net. So here we explain the main categories of assurance cover you should be looking at, though few people will be able to afford (or need) them all.

The risk of Huntington's disease means that not all assurance products may be available, and where they are, the additional cost levied by the Insurer may affect the affordability.

Firstly, with all these plans, you have to decide whose life to insure – your own life or your partner's, or both your lives on what is called a joint-life basis. An ordinary life assurance policy taken out on a 'Joint-life, first death' basis means the pay-out is made on the death of either partner – whoever dies first. You must also decide how much life assurance you need.

Sit down and work out with your partner exactly how either of you would cope financially if one of you died or lost your income through illness.

Protecting a person who is or may be at risk is very important but do not forget the individuals who may become carers in the future, their financial well-being is also vitally important.

How much cover?

Key questions

- How much would the family income drop if I were to die or become unable to continue working?

- How much would outgoings increase on things like childcare if I became too ill or disabled to do it myself?

- How much cover do I get from my employer or company pension scheme? Do they cover death? Do they cover illness and disability and if so, for how long?

- What assurance policies do I have already and how far do these go to meeting my needs? • How far will our savings go?

- What state benefits are there to cover the family needs?

Calculating cover requirements

In practice the sums required aren't easy to calculate because of individual circumstance. For most families the most important material loss would be the security that the family home brings. The chances are that any outstanding mortgage debt will already be covered through the assurance you took out when you arranged your mortgage, though you need to check this out.

There are all the other costs which the surviving partner would have to meet in bringing up a family and struggling to maintain the same sort of standard of living. If there is only one breadwinner – and he or she dies – then the financial implications are obvious. But equally, if the partner who spends most of the time at home dies, the monetary value of their contribution to the family budget should not be overlooked.

The average family would need a pretty large lump sum – even if it was invested prudently – to generate enough income to keep the family finances on an even keel, whichever partner died (for each £8,000 a year needed, a lump sum of £160,000 would probably be required at today's interest rates).

Finally, don't forget the debts that may need to be paid off if you die – in addition to any mortgage. These may be quite large, particularly if you are running your own business.

Once you've done all the sums, you could well find your life assurance needs are higher than expected.

How much cover do you need?

Make sure you take income from all sources and from both partners into account when calculating how much life assurance cover you need to maintain your family's existing standard of living. How much of this is absolutely indispensable and how much is surplus? And if one of you doesn't do any paid work, you must calculate the value of their unpaid labour in the home. You may not be able to avoid paying out in this way if the one that is left is able to go out to work.

The family's expenditure: it is reasonably easy to calculate how much you spend each year on maintaining your household and how much a surviving partner would still need to maintain the family home, feed and clothe the family, and look after the everyday expenses.

Your debts: on your death: firms that loaned you money could demand immediate repayment out of your estate. Also, don't forget the debt you may have run up on your credit cards, along with any unsecured loans. If you run your own business, there may be business debts as well.

Your children: the older children get; the more expensive children seem to be – so allow for future as well as present costs.

Divorced: if you are divorced, would you want maintenance payments, for your children in particular, to stop if you died? And if you are at the receiving end of the maintenance payment, what about taking out life assurance on the life of your ex-partner?

Business Partners: if you are running a business, you may need to insure either your own life, or the lives of your colleagues, under "keyman", or partnership cover.

Your car: is it a company car? If so, any replacement might have to be financed out of personal income.

The types of cover available

Term Life Assurance (Term Assurance)

This is the simplest and cheapest form of life assurance available. Term assurance policies run for a set number of years and then expire with no surrender value. If premiums are missed then the cover will lapse after a given period.

The two most common forms of term assurance are, level term and decreasing term.

- Advantages
- Simplest and cheapest form of life cover and generally easy to obtain.
- Client can choose the length of the policy term.
- Some policies can link the amount of cover to inflation.
- Ideal cover for repayment mortgages.
- Usually there will be no tax charge on policy benefits.
- Can be written under a trust to ensure benefits may be paid to specific individuals.

Disadvantages

- On some policies, the premium can be increased by the insurer during the policy term; these are called reviewable rates policies. Guaranteed rates plans are also available, but usually cost a little more.

- Premiums paid provide life cover and nothing else.

- Cover will decrease in real terms unless inflation proofed.

- No surrender or maturity value attached to the policy

Whole of Life Assurance

This is a permanent life assurance policy which (assuming the policy premiums are up to date) will pay out whenever the life insured dies.

As it is certain that there will be a claim at some stage, the premiums will be more expensive than for a comparable term policy.

Advantages

- A permanent policy that pays out whenever the life insured dies.

- Competitive pricing is useful for mitigating an inheritance tax liability.

- Can be paid for either by regular monthly, annual or a lump sum.

Disadvantages

- More expensive than term assurance.

- Low surrender values in the early stages of the policy – you may get back less than you paid in.
- It must be regarded as a long-term commitment.

Premium

- Policies can be adapted to suit changing needs.

- Policy can combine an investment element or provide a guaranteed benefit.

- As most policies are investment linked, there are a wide variety of investment funds to choose from which may enhance the policy value.

Family Income Benefit Policies

Instead of a term assurance paying out a lump sum on death, it is possible to have a policy which pays out a regular income to replace that of the life insured. The income is paid either monthly, quarterly or annually from the death of the life insured until the expiry of the policy. Alternatively, a cash lump sum may be taken instead of the regular monthly or annual payment.

Advantages

- Useful for beneficiaries of a policy who would not want to handle large capital sums.

- Relatively cheap.

- It may be possible to arrange a policy with increasing benefits

Disadvantages

- If the life insured dies towards the end of the policy term, then only a few payments will be made to the beneficiaries.

- Unless linked to inflation, then the benefits will decrease in real terms over the life of the policy.

Critical Illness Cover

Critical Illness cover pays out a lump sum benefit if the applicant suffers from one of the covered conditions such as heart attack, stroke, cancer, coronary artery bypass graft, kidney failure, heart valve surgery, you are unlikely to get critical illness cover for HD. The range of conditions covered will vary depending on the insurer.

Critical Illness cover can be added to any of the above assurances or it can stand alone on any of the basis above.

Income Protection

Income Protection, often called Permanent Health Insurance, is designed to pay an income benefit when you are unable to work through illness or disability. These benefits when arranged on an individual basis are usually tax free. The purpose of this cover is to prevent financial hardship when you suffer from a period of illness that prevents you from working

The disability or illness can be temporary or permanent and is usually measured by one's inability to perform your occupation. The income benefits would continue to be paid up until the earliest event; your recovery, your retirement date, your death, or the expiry date of the policy you had selected at the outset.

Some policies pay benefits which increase annually in line with inflation or earnings. Premium rates vary according to sex, occupation, smoker status, and other health related factors. Your occupation is particularly important because some jobs contain a greater risk of injury or illness than others. In addition, the longer the period from the onset of your disability to when benefits are payable: the lower the premiums.

Waiting periods are usually 4, 8, 13, 26 or 52 weeks. These waiting periods are selected normally so that benefit begins once your entitlement to sick pay, if any, from your employment ceases. The amount of benefit you receive during disability or illness will be limited so that your total income does not exceed a proportion of your income prior to disability
This proportion usually allows for the fact that the benefit is paid tax-free and will include other income such as State benefits.

Mortgages

Many people at risk from Huntington's disease think that they will be excluded from taking out a mortgage. This is a popular misconception.

The vast majority of lenders no longer insist upon life assurance as a condition of the mortgage

Pensions

Income in retirement is a serious concern for individuals at risk from Huntington's disease. Many people are concerned as to what benefits they may receive from their company pension scheme if they are forced to retire early through ill health or to care for a person affected by HD. There are often thoughts of 'why bother to save for retirement if I may not be around to enjoy the money' and others are concerned about what happens to accumulated pension funds if they die. You may be considering joining your company pension scheme and wondering whether you will be allowed. All of these and many more besides are valid concerns which must be addressed.

Pensions are one of the Governments largest financial concerns. As time goes on the burden upon the State of pension provision is increasing as people are generally living longer. Proportionally there are far more people in retirement than ever before putting an increasing burden on state pension.

Medical technology, as well as vast improvements in diet and lifestyle; have meant greatly improved standards of living resulting in individuals living much longer than ever before. If this trend continues it is estimated that by the year 2050 there will be one person working for every three retired.

The Association of British Insurers Genetic Testing Code of Conduct

The Association of British Insurers (ABI) is the trade association for the UK's insurance industry. The ABI represent around 400 companies that provide all kinds of insurance including Life, Critical Illness and Income Protection cover

A moratorium on the use of genetic testing for insurance has existed since 1997 and with revisions will continue. This stipulates some rules, which all members of the ABI must follow. The following is a list of key obligations that all insurers must follow;

- No insurer will request that an applicant undertake a genetic test in order to obtain insurance.

- The results of any genetic test will not be used in the assessment of an application, unless they are in the applicants' favour, or the test has been approved by the Genetics and Insurance committee (GAIC)

The tests which have been approved by GAIC can only be used on cases above the following limits:

- Life insurance in excess of £500,000; · Critical Illness in excess of £300,000;

- Income Protection cover in excess of £30,000 per annum.

- All companies to record all cases on which a genetic test has been disclosed

- All companies to nominate a genetics underwriter and deputy.

Up to 2012, the only test that has been approved by GAIC is the test for Huntington’s disease.

Whilst a positive test for Huntington’s disease cannot be used in the assessment of an application for Life, Critical Illness, or Income Protection Cover (below the agreed limits), the Insurer can still use family history information and this is often requested on an insurance application. Most insurers would use a negative test for Huntington’s disease to allow the family history to be ignored and a normal terms policy to be issued.

Details of the moratorium can be found at www.abi.org.uk

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Fact sheets available from the Huntington's Disease Association:

- General information about Huntington's disease and the Huntington's Disease Association
- Predictive testing for Huntington's disease
- Talking to children about Huntington's disease
- Information for teenagers
- A young adult's guide
- Eating and swallowing difficulties
- Huntington's disease and diet
- The importance of dental care
- Communication skills
- Behavioural problems
- Sexual problems
- Huntington's disease and the law
- Huntington's disease and driving
- Advice on life assurance, pensions, mortgages etc.
- Seating equipment and adaptations
- Checklist for choosing a care home
- Advance Decision to Refuse Treatment (ADRT)
- A carer's guide
- Challenging behaviour in Juvenile Huntington's disease
- A brief guide to Juvenile Huntington's disease for children's hospices and palliative care services
- A teacher's guide
- A young person with Juvenile Huntington's disease at school

All fact sheets can be downloaded free of charge from our website www.hda.org.uk or ordered by phone 0151 331 5444 or email info@hda.org.uk

For a publication price list/order form, membership form, details of our Specialist Huntington's disease Advisers and local Branches and Support Groups, please phone 0151 331 5444 or email info@hda.org.uk

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