

Consultation Response

Statement of Best Practice for Critical Illness Cover
2009 Review Consultation Paper
Association of British Insurers



Response by the Genetic Interest Group and Ataxia UK

Introduction

The Genetic Interest Group (GIG) is an umbrella organisation acting on behalf of 138 member organisations who support and care for patients and their families affected by health conditions with a genetic component. Many of the conditions supported by our members are severe and lack a cure or treatment; many are rare and therefore poorly understood by anyone outside of a small pool of disease specific experts.

Ataxia UK is the national charity for people affected by ataxia and is a member of GIG. Ataxia UK has been supporting people with ataxia and their families for over forty years. They provide unique services and support, including a dedicated helpline and advocacy service.

Ataxia is a life-limiting, progressive neurological condition. Ataxia means 'lack of order', because it gradually makes you lose control of your body. People with ataxia have problems with balance, speech, and co-ordination. This is because parts of the nervous system that normally control co-ordination and balance are affected. There are many different types of ataxia with different causes and symptoms; many are inherited. Thanks to Ataxia UK research it is now known that more than 10,000 people in the UK have ataxia; thousands more than was previously thought.

Ataxia is progressive, meaning it gets worse with time, until people become entirely dependent on others for all their needs. There is currently no cure. Ataxia UK's ultimate goal is to find a cure for the condition.

Ataxia UK have provided a case study of their member Stuart Mounsey's experience of Critical Illness Cover, which is referred to in this document and is attached in the annex.

The patients the Genetic Interest Group and Ataxia UK support face communication difficulties relating to the complexity of their condition in many aspects of their lives. Access to education, social support, and even some areas of the health care system can be difficult due to the necessity of labelling their condition and communicating their needs to those who may not be aware of their condition. Insurance is one service which our members find difficult to access; and GIG has worked with the Association of British Insurers in the past on various projects to attempt to improve the experience for our members. We have published advice on obtaining travel insurance and are currently running a project "Asking Relevant Questions" which will speed up the application process for insurance and make it more transparent for patients.

We welcome the Association of British Insurers' consultation and are grateful for the opportunity to comment.

Question 1 – Given the claims experience and number of declined claims of the current TPD definitions within CI, do you agree the industry is right to take actions and address this issue?

We agree that action in this area is over due.

More than half of Total Permanent Disability (TPD) claims have been refused. GIG and Ataxia UK believe that this demonstrates that the public have a poor understanding of what the TPD component of their Critical Illness cover has been delivering. It is important for any consumer to fully understand the product that they are purchasing, and the case of Critical Illness cover is no different. Action to improve consumer education and information in this area is clearly over due.

Question 2 – Do you agree with the approach to produce a set of definitions covering the underlying causes of TPD; if not do you have alternative proposals?

We do not agree with the revised proposals.

Critical Illness cover should provide exactly that: cover for those affected by an illness which is having a critical effect on their lives.

Any set of definitions of conditions which are considered to be critical cannot be exhaustive. If TPD is to be removed from policy definitions, its replacement should seamlessly cover the gaps left behind and increase the transparency of policies to the consumer. We do not believe the new approach meets these criteria.

Indeed, we understand from sources within the industry that the proposed revisions would result in a lower proportion of current TPD claimants being paid.

This new approach creates a further cohort of conditions which a patient may consider themselves 'lucky' to contract, as they are permitted to claim on their critical illness cover. The set of categories proposed includes Parkinson's Disease, but rules out 'Parkinsonian Diseases', despite the experience of a patient with either diseases being largely similar.

The case study (available in the annex) of Stuart Mounsey, a member of Ataxia UK, demonstrates this issue. He was diagnosed with Progressive Cerebellar Ataxia in February 2006 but could not claim for the condition because it was not on the list of conditions specified on his Critical Illness policy. Stuart was only able to claim once his illness had worsened to the extent that it satisfied the definition of TPD. If he had been diagnosed with Multiple Sclerosis (a very similar, but far more common condition), one of the few conditions named on his policy, his payment would have been made two years earlier.

There are over 6000 rare diseases affecting more than 3.5 million people in the UK. Category sets, such as those proposed, would not cater for these consumers.

We recommend that any change from the current system should move towards a more uniform approach to all critical illness, creating a system which truly supports those unlucky enough to contract an illness which has a critical effect on their life.

Question 3 – Do you agree with the proposal to introduce a model definition for 'Loss of the physical ability to look after yourself'?

We agree with the proposal to introduce a model definition for 'Loss of the physical ability to look after yourself' but do not believe that the proposed solution is fit for purpose.

The proposal is a step in our favoured direction i.e. away from disease specific criteria, however, the 'three of the six' approach seems to be basic and arbitrary. We would also like to see further detail as to who would be the judge.

Health Technology Assessment, a process developed to judge the efficacy of drugs, treatments and other healthcare products, employs many sophisticated tools to measure a patient's quality of life before and after treatment. We propose that methods such as these, which have been developed to a fine degree of accuracy and are able to cope with and normalise many differing symptom groups, would be a better, and far fairer, indicator of how critical a patient's illness is.

Tools such as the SF-36 Health Survey (which uses eight criteria: bodily pain, physical functioning, role limitations due to physical health, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health) and Euro QoL (which uses five criteria: Mobility, Self-care, Usual activities, Pain/discomfort, Anxiety/depression) could be adapted for use in this industry, and would provide a fine degree of accuracy absent from the current proposal.

Question 6 – Do you support the intention to create a clearer distinction between CI and IP benefits by preventing insurers including occupational based TPD definitions relating to the lump-sum CI benefit?

We do not support the prevention of inclusion of occupational based definitions in CI policies, unless the replacement definitions can be shown to provide a similar cover.

In our case study, Stuart Mounsey benefitted from the inclusion of an occupational based definition of TPD. This definition reflected the impact of his ataxia on his life, and resulted in a successful claim. Stuart Mounsey could not have made a successful claim against a policy using the proposed revisions because his condition, though debilitating, would not fit with the definitions; it was only the "real-life" occupational definition that allowed him to achieve a successful claim.

We would therefore propose that customers are encouraged to take out IP policies alongside CI policies, either as a hybrid package or as complementary policies, to ensure a better degree of coverage.

We support all intentions to make CI cover a more transparent product, as we believe the consumer should be able to easily understand the breadth and depth of their cover.

In summary:

- we agree that action regarding current TPD definitions is overdue;
- we do not agree with the proposed solutions which appear to be basic and arbitrary;
- we do not believe that the proposed solutions will resolve the current inequities associated with CI insurance;
- we do not agree with the current proposal to prevent occupation based TPD definitions;
- we support the intentions to make CI a more transparent and understandable product.

We will be happy to expand further on any of the points made here.



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Annex

Statement from Stuart Mounsey – a member of Ataxia UK

17 September 2009

I was first diagnosed with ataxia in February 2006 following an MRI scan of the brain – to this day the type of ataxia I have remains unknown, in spite of undergoing many tests.

In April of that year, I tried to claim on my Critical Illness insurance policy that I held with Royal Sun Alliance. They were taken over by another company since I took out the policy, and are now known as Phoenix.

The categories which I could claim under were limited to just six, the closest category to ataxia being multiple sclerosis.

Their definition was thus:

'The date of unequivocal diagnosis of multiple sclerosis by a consultant neurologist confirming more than one episode of well defined neurological deficit with persisting signs of involvement of the optic nerves, brain stem and spinal cord together with impairment of co-ordination and motor sensory function existing for a continuous period of at least six months'.

I was told by the insurers in July of that year that I couldn't claim under that category, even though I was diagnosed with progressive cerebellar ataxia and all my symptoms were consistent with their definition of neurological deficit.

Sometime later I saw a piece on the BBC's 'One Show' asking for people who were having problems with Critical Illness insurance policies to get in touch with them. I filled in the online questionnaire, and subsequently was interviewed by one of the 'One Show' presenters, Dominic Littlewood, at my home in October 2007.

The interview was screened by the BBC in November 2007.

Also in November 2007, with renewed vigour, I appealed against the original decision again, only to be told once again that I was unable to claim.

In mid February 2008, I was released from my employment on health grounds. I again applied to Phoenix, this time claiming under the 'Total Disability' section.

This time the claim was successful, and the insurers had to pay out.

Stuart Mounsey

Member of Ataxia UK