

DRAFT SPEECH

1. I congratulate my hon friend the Member for Bolton South East on his success in obtaining this debate, as I know that he has taken a special interest in hepatitis C and people affected by it. I am grateful to him for giving me the opportunity to set out the Government's position on hepatitis C and our commitment to tackling it in a strategic, co-ordinated and robust manner.
2. To put this in context, let me start by setting out the key facts about hepatitis C so that the nature and scale of the problem is apparent.

Hepatitis C infection

3. The hepatitis C virus was identified in 1989, and the significance of its association with chronic liver disease or the numbers of people infected was not initially appreciated. However, as my hon friend says, hepatitis C is now recognised as a global public health problem.
4. In England, studies suggest that we have a relatively low prevalence of hepatitis C, perhaps one of the lowest in the world. Best estimates of the number likely to have been infected and to have become chronic carriers are probably around 250,000. As a comparison, this is nearly 10 times the estimated figure for those infected with HIV. However, unlike HIV, we do have a drug treatment that can clear the virus in many of those infected, but there is no room for complacency.

Transmission of hepatitis C infection

5. Hepatitis C is spread by contact with the blood of someone who is infected. Injecting drug misusers and those who received blood transfusions or blood products before screening and viral inactivation processes were introduced, have been the main groups potentially at risk. To a much lesser extent, hepatitis C may also be spread between sexual partners and from mother to baby. Health care workers are also at risk from occupational exposure.

6. Once transmitted, the virus may quickly cause inflammation of, an acute illness from which people recover. However, for perhaps 80%, the infection becomes chronic and has longer-term health implications.

Progression of disease

7. People with chronic HCV infection can remain virtually symptomless for many years, and a large number will live out their normal lifespan. However, individuals may suffer more general debilitation effects that can affect their quality of life. Over time, in a proportion of cases, the liver may become progressively inflamed and damaged. If not treated, this may eventually progress over a number of years to severe liver disease, or occasionally liver cancer, causing the liver to fail and for the patient to require a transplant. In addition, there is anecdotal evidence that some people with hepatitis C may experience social prejudice and discrimination, which, in part, may represent a lack of public knowledge about the disease.

8. Routine death statistics suggest that around 100 people die each year from an underlying cause of hepatitis C infection in the UK. But is it clear that hepatitis C infection will also contribute to deaths from the complications of chronic liver disease, including cirrhosis and hepatocellular cancer, and there is likely to be some under-reporting. As I will mention later we are looking at ways of improving the surveillance of serious liver disease associated with hepatitis C.

Treatment

9. NICE (the National Institute for Clinical Excellence) has assessed the use of a drug combination therapy of ribavirin and interferon for treating hepatitis C, and published its recommendations in October last year. This therapy has been shown to be twice as effective as any previous treatment. NICE's recommendations provide clear and authoritative advice for clinicians and health care providers, and should help to ensure that patients get effective treatment.

10. We have made additional funds of £275M extra for the next three years available to the NHS to meet the costs of NICE recommendations. This funding is over and above that announced in the 2000 budget, where the Chancellor announced the biggest sustained increase in funding in NHS history. My hon friend suggested we go down the path now of having some kind of ring-fenced budget for hepatitis C treatment. This would remove local flexibility in assessing and providing for local needs.

11. There are grounds for optimism too that further improvements in treatment will follow. A modified, slow-release form of interferon – pegylated interferon – became available earlier this year April 2001 which appears to be more

effective than conventional interferon. We are considering referring this for appraisal by NICE.

12. There has been concern expressed that the NICE guidelines seem to exclude injecting drug users from treatment for hepatitis C. This is not true. Although there is general advice which recognise potential difficulties in treating injecting drug misusers, NICE recommends that if a prescribing clinician is reliably assured that re-infection, compliance and drug interactions pose no problems, a person in this group might be considered to combination therapy. In line with good medical practice, the emphasis should be on the clinician assessing each case individually in conjunction with the patient. And as my hon friend has said, there is some evidence that injecting drug users may be successfully treated for hepatitis C.

Clinical guidelines

13. The Royal College of Physicians, the British Society of Gastroenterology and the British Association for the Study of the Liver published evidence-based clinical guidelines in July this year. These will provide a framework for patients with hepatitis C to receive high-quality treatment and care, and I am pleased to say that this work had the full support of the Department of Health.

Improved commissioning and training of specialists

14. We recognise the increasing importance of hepatology not only for patients with hepatitis C but also for those with other complex liver diseases who should have access to specialist hepatology units with the necessary knowledge and expertise. We have discussed this with leading liver organisations including the British Liver Trust and the British Association for

the Study of the Liver (BASL).

15. We have agreed that the BASL should apply formally for recognition as a sub-speciality of Gastroenterology for training purposes. This will secure a supply in the future of fully trained hepatologists who are able to care for these patients.

16. We have also been working on a commissioning framework to ensure that specialised hepatology services are developed to uniform standards throughout the country. The National Specialised Services Definitions Set is due to be published by the Department later this month, and it will be used as the basis for identifying those specialised services which require some form of collaborative commissioning. Hepatology, which includes specialised services for the treatment of patients with viral hepatitis, is part of this set.

Haemophiliacs with hepatitis C

[Drafting note: ? item about possible care package]

17. As I said, hepatitis C infection can be acquired in a number of ways, and, in the past, contaminated blood and blood products were a major route of transmission. Sadly, during the late 1970s and early 1980s, the majority of regularly treated patients with haemophilia were infected with either HIV or hepatitis C. The technology to make blood products free from hepatitis C in sufficient quantities to treat all haemophiliacs in the UK was simply not possible prior to 1985. Once it was the NHS introduced it.

18. As a result, around 4-5000 haemophiliacs are estimated to be infected with hepatitis C and around 500 are still living with HIV. Most of those with HIV are also infected with hepatitis C, and this co-infection may accelerate the clinical course of both disorders as well as making the haemophilia more

difficult to manage. They therefore face considerable medical and psychological problems over and above those faced ordinarily by people with haemophilia.

19. The Government has enormous sympathy for haemophiliacs in this situation. It is therefore essential that the NHS is properly geared up to delivering the full range of clinical and support services needed by people with haemophilia and treatment acquired infections.

20. I want to respond to the points made by my hon Friend (and others), beginning with the call on Government to provide financial assistance for people with haemophiliacs and hepatitis C and their dependants.

Compensation

21. As Members of this House are well aware, we met the Haemophilia Society in 1997 and listened to their arguments for a special payments scheme for people with haemophilia and hepatitis C similar to that in place for HIV. After long and careful consideration, we came to the same conclusion reached by the previous Government - that a special payments scheme should not be established.

22. Succeeding Ministers have reviewed this decision and reached the same conclusion. It has also been debated on numerous occasions in both Houses. It is not a view we have come to lightly. I can assure my hon Friend that everyone of my colleagues who has looked at this issue, and met individuals directly affected by this tragedy, has found this a most difficult position to arrive at.

24. We believe that financial needs of people whose condition results from inadvertent harm should be met through the benefits system. I know that the Haemophilia Society does excellent work ensuring that people with haemophilia are made more fully aware of their benefit entitlements.

25. It has been the policy of successive Governments that compensation or other financial help to patients is only paid when the NHS or individuals working in it are at fault. The underlying principles are clear cut and independently established under common law. They apply to personal injury cases in general - not just those arising from health care. There have been no new developments to change this long-standing policy.

High Court Judgement

26. We are continuing to focus on the implications of the decision in the High Court to award damages to 111 people infected with hepatitis C through blood transfusion before the introduction of screening for the virus in September 1991. This case was brought under the Consumer Protection Act 1987 which introduced strict liability for products judged to be defective. However, this judgement does not impact on the question of compensation for haemophiliacs with hepatitis C, who were infected before the Act came into force in March 1988.

Payments to Haemophiliacs with HIV

27. Comparisons have been made between the decision not to offer special payments to haemophiliacs with hepatitis C and the special payments established in the late 1980s for haemophiliacs with HIV and the ex-gratia payments we are making to people with variant CJD and their families. However, there are significant and real differences between these situations.

28. In the case of HIV, we need to think back to the circumstances of the late 1980s when HIV was having a vast and dramatic impact. It was a source of fear and stigma for all those who became infected with the virus. There was widescale public reaction. HIV then was a new sexually transmitted infection which was rapidly fatal. There was no treatment and, at that time, death from AIDS related diseases was considered inevitable.

29. It was in this context that special payments were introduced and the Macfarlane Trust was established. We see this as a reflection of those truly exceptional circumstances and the very poor prognosis at that time for people with haemophilia who became infected with HIV.

30. Whilst the Government has agreed ex-gratia payments for victims of variant CJD in the wake of the Phillips Inquiry, the circumstances and background to this situation are again truly exceptional. It therefore does not change our long-standing policy on compensation for injuries caused by the NHS, which I firmly believe is the right one.

31. Our aim now is to move forward - to enable people with haemophilia and hepatitis C to get on with their lives and to look constructively at how we can improve their health and well-being here and now.

Injecting drug misuse

32. Currently, unfortunately up to about 80% of hepatitis C transmission is associated with injecting drug misuse, because of the sharing of contaminated injecting equipment. We are therefore already increasing our efforts to prevent new cases occurring in this manner and ensuring that injecting drugs users with hepatitis C get specialist advice.

33. Our strategies to prevent infection and minimise harm include:

- reducing the level of sharing through provision of needle exchange schemes and through health promotion activity in treatment agencies;
- preventing people starting to inject drugs;
- encouraging current injectors to stop injecting; and
- encouraging those who are infected to reduce their alcohol intake and stop all behaviour likely to infect others.

34. Needle exchange facilities are now provided in all regions and by nearly all health authorities. There is increasing evidence that the overall prevalence of hepatitis C amongst injecting drug misusers is less than expected (about 40%) and that they have a greater risk of becoming infected the more their injecting career lasts. This suggests that needle exchanges and other harm reduction measures are playing a key role in reducing the spread of hepatitis C and there is a valuable window of opportunity for prevention.

35. We published guidance on hepatitis C for those working with drug users in April 2001. This guidance should ensure that professionals give drug users clear and consistent messages to reduce the risk of infection and to reduce harm associated with hepatitis C infection for those already infected.

36. We have also funded regional seminars, which were held earlier this year, to raise professional awareness of hepatitis C and how to reduce the risk of transmission and later ill health. Almost 400 drug workers, managers of services

and commissioners of drug services attended these events. And we are intending to fund a further series of seminars later this year.

Development of a national strategy for hepatitis C

37. Against the background that I have described, we fully recognise the importance of hepatitis C as a public health issue and the need to have in place effective prevention, testing and treatment services. We are committed to having a robust and effective strategy for hepatitis C, which will reduce hepatitis C transmission and benefit those with hepatitis C. To assist us in developing our strategy, we set up a multidisciplinary steering group in March this year.

38. The steering group is chaired by Professor Howard Thomas of Imperial College School of Medicine, who is a world authority in this field, and comprises health professionals, academics and voluntary/community sector members. We have asked the group to produce a draft consultation paper for the Government to consider by the end of this calendar year. The steering group is currently on track to do this and we hope that the consultation paper will be published early in the New Year.

39. The steering group is considering the scope and effectiveness of current measures to tackle hepatitis C and advising us on any gaps or areas for improvement. Part of its work has already involved commissioning work to estimate the future disease burden associated with hepatitis C and to model the effectiveness of preventive interventions. This will assist in planning future health care needs and targeting our efforts to prevent new infections.

Conclusion

40. In conclusion, we are already making considerable efforts to tackle hepatitis C and are developing strategic approach to strengthen and improve activities to prevent hepatitis C infection, increase diagnosis of those with infection so that they can be referred for specialist assessment and work towards ensuring that specialist hepatology services are developed to uniform standards throughout the country.

41. Our proposals will be published in a consultation paper early in the New Year, which will be underpinned by the core values and principles of the NHS Plan.