COMMITTEES: Community Affairs References Committee: Report

Senator McLUCAS (Queensland) (10.20 a.m.) —I present the report of the Community Affairs References Committee on Hepatitis C and the blood supply in Australia, together with the *Hansard* record of proceedings and documents presented to the committee.

I am pleased to present the report of the Senate Community Affairs References Committee inquiry into hepatitis C and the blood supply in Australia. Before we began this inquiry, my understanding of the nature and the extent of this issue was limited and I think this lack of understanding is shared by most Australians. I am fortunate that I have been able to learn about the nature of the issues facing people who have contracted hepatitis C through the blood supply. I hope that through this inquiry and report there will be a greater and broader understanding of hepatitis C in this nation. I felt the lack of understanding of hepatitis C infection that I had was telling. This lack of understanding is itself part of the problem. The fact that we do not know the number of people who have hepatitis C or how they contracted it is a problem that needs to be overcome.

During the inquiry, we heard from the Australian Red Cross Blood Supply and CSL, from doctors and researchers working in the hepatitis C field, from the hepatitis councils and from a range of groups who represent those who have contracted hepatitis specifically through infected blood. We also heard from the Department of Health and Ageing and very importantly from individuals who shared their stories both confidentially and publicly and who live day after day with the reality that they have contracted hepatitis C through a simple ordinary medical procedure. I think that fact must not be overlooked. People went to hospital to have a baby or to undergo a normal procedure and had to have blood. As a result of that medical event, they now have a disease that is life changing for them.

We know that between 3,500 and 8,000 Australians who live with hepatitis C received that infection through the blood supply, including about 1,350 people who are haemophiliacs. The tragedy, though, is that many people who have hepatitis C do not know it. A recommendation in our report will hopefully assist with that identification. The first recommendation of our inquiry asks the Health Ministers Advisory Council to consider the introduction of a mandatory reporting mechanism. It is mandatory to report hepatitis C infections but that reporting occurs only between the doctor and the state. Our committee recommends that a further mandatory reporting mechanism be instituted to ensure that a database is collected nationally of people who, it is thought, contracted hepatitis C through the blood supply.

Hepatitis C affects all aspects of the infected person's life. As I said, it is a life changing disease. There are many debilitating symptoms such as fatigue, pain and commonly depression. Some people develop cirrhosis of the liver, liver failure and even liver cancer. Many people with hepatitis C cannot continue to work. For some it has affected their relationships with their family and their friends. We heard many sad and tragic stories, which were common stories, unfortunately, of broken marriages where the pressure of the disease affected the relationship to such an extent that it was not possible to continue.

People with hepatitis C also face ignorance, discrimination and stigma. This is very distressing, particularly when it occurs in health care settings. We heard many tragic stories about people who presented to the medical profession but the lack of understanding of the nature of hepatitis C by the medical profession meant that those people were dealt with very poorly. As a result of this discrimination, many people with hepatitis C often choose not to inform their family or their friends about their health status for fear of rejection or ostracism.

The committee heard from a number of respondents who felt that Australia's decision not to introduce surrogate testing—which was the only form of testing available prior to the introduction of more accurate antibody testing in 1990—for hepatitis C was wrong. The committee was also very aware of the widespread controversy surrounding the use of surrogating testing for hepatitis C in Australia. There is evidence that the relevant authorities in Australia could have begun surrogate testing for hepatitis C and that this might have had a small benefit. However, the committee was also presented with a great deal of compelling evidence as to why surrogate testing was not introduced. It seems to the committee that it was open to the relevant bodies, based on the information available at the time, to take the decisions that they did. The committee is confident that due consideration was given to pertinent evidence at relevant times and that decisions were reasonable in the circumstances.

The committee were also asked to consider the implications for Australia of the world's biggest inquiry into blood—the Canadian commission of inquiry chaired but Justice Horace Krever. We considered that report and, although the Krever report provides a useful analysis of the state of knowledge at the time, the committee believes there was a different context between Canada and Australia in which those decisions were being made. The key difference is that in Australia all blood is given on a voluntary basis whereas in Canada and in the United States people are paid for their donations of blood. That is the significant difference.

The committee were also asked to examine Australia's involvement in compensation schemes for people who contracted hepatitis C through the blood supply. Compensation schemes exist in the states and territories for those who are infected with hepatitis C through blood. Witnesses pointed to the restrictive nature of these schemes and to confidentiality requirements. There were calls to increase and extend the compensation schemes. While we acknowledge these calls, stronger and louder calls were heard by the committee for greater access to health services, including psychology and psychiatry, improvement of education of medical personnel and support for research efforts to develop more effective treatments for hepatitis C.

We have a range of recommendations in our report, which are in the overview at the beginning of the document. I think the most important recommendation and one that will change health outcomes for people who have hepatitis C is recommendation 6. The committee recommends that we set up a national post-transfusion hepatitis C committee with the purpose of, firstly, formulating, coordinating and delivering an apology to those who have acquired hepatitis C through the blood supply. I acknowledge that the ARCBS very recently met with some of those who contracted hepatitis C—and people would have seen that in the media—to start that process. That is good. I encourage other participants in this discussion to be part of that process, including governments and potentially including CSL.

This committee will also work with the states, the territories, the Commonwealth and the Red Cross to establish an effective look back program. I am sure other speakers will talk more about that. Most importantly, we recommend that a fund be established—funded by the states, the Commonwealth and potentially the Australian Red Cross Blood Service—that can be accessed by people who have contracted hepatitis C through the blood supply. We say: `If you think you got hepatitis C through the blood supply and you know you had a transfusion, let us help you. Let's not go down the legal path; let us simply get you some support.' There are varying levels of support across the country, and there are many people who are not getting the level of support that they need. I commend the report to the Senate. I put on record my thanks to the committee and to Elton Humphery, Christine McDonald and Tim Watling for their service to the committee. I particularly thank those individuals who have contracted hepatitis C through the blood supply and shared their stories with us.

Senator KNOWLES (Western Australia) (10.31 p.m.) —Today the Senate Community Affairs References Committee's report *Hepatitis C and the blood supply in Australia* has been tabled. I have been on many committees in my 20 years in this place, but this would have to rate among the three saddest committees I have ever been on. The issue has touched the lives of Australians in ways in which many of us would never understand. I certainly did not understand the severe implications of contracting hepatitis C until we got down to the nuts and bolts of this inquiry. The sad, horrible, graphic stories that people told us cannot but touch hearts as we try to help our fellow Australians overcome something they contracted through no fault of their own—there was no form of stupidity involved or any rashness in their behaviour; they contracted a virus through a blood transfusion.

It is enormously sad that people who have been involved in traffic accidents or have undergone major surgery require blood transfusions, because those people—the doctors and everyone else—act in good faith, but haemophiliacs require blood products just to live. They too have been affected and infected by this virus, which is part of the reason why the committee has recommended that governments look at the availability of the recombinant factor, in conjunction with the plasma derived products, to ensure total safety. Plasma derived products have been proven to be absolutely safe since the early 1990s—I am not trying to create fear; I am just saying that a number of people want an option.

Another tragedy is that a lot of people in the community do not even know that they have contracted hepatitis C. They know they are ill and they have sought help, but they have not been identified as sufferers. That is where the system has fallen down in many areas, insofar as many in the medical profession seem unable to provide an immediate diagnosis for sufferers. People have been sent away, having been told that they have a virus or chronic fatigue syndrome or that they are run down, whereas if they had tests that confirmed the problem they would be able to access treatment.

People are affected in a multitude of ways. Some of them cannot manage day to day things such as getting out of bed or caring for their children. They have difficulty getting to appointments. Probably worst of all is that in many cases they suffer discrimination. The lack of public awareness of hepatitis C means sufferers can face enormous discrimination, because people tend to think they have contracted hepatitis C through unsafe practices, body piercing or tattooing. The tragedy of it is that a lot of those practices are still being engaged in by young people—they do not know the risk that they are exposing themselves to today.

Another recommendation of the committee is for a better public education and awareness system whereby people who are sick can be alerted to the fact that, if they had a blood transfusion some years ago or if they had undertaken some unsafe practices some time ago, they might have hepatitis C. We should help them identify and manage their problem and alert people to the practices that can put them at risk in the future. The federal government has provided millions of dollars to the states and territories for an education campaign. To the best of my knowledge, the states and territories have put that money into identification and management programs, which I believe should be undertaken by the colleges of general practice. Be that as it may, that money has been put into that area. It is, therefore, a recommendation of the committee that we look at a better public education and awareness campaign that would use the broad media, television, radio, newspapers, and possibly even mail to every household. This situation is so serious that we cannot just hope that it will disappear and that people might be more aware. We need to undertake an education campaign to make people more aware.

I think that looking for people to blame is a very natural response for these innocent people, but the overwhelming evidence was that, as Senator McLucas has said, people wanted help. They wanted help to manage. They said, `Just getting a huge dollop of money is not going to help me look after my kids. It's not going to help me access medication. It's not going to help me get to appointments.' They want this help, and that is why we have recommended that consideration be given to more help being available to the people who are affected.

It has to be said that the ARCBS acted on the best available advice at the time not to introduce surrogate testing, and they have recently provided an apology. I think the important thing here is that the surrogate testing has proved worldwide to give false positives and false negatives at unacceptably high levels. Queensland was the state that did introduce surrogate testing, and the committee found that it had about a 70 per cent rate of false negatives. As I said at the time in a hearing, I would have been pretty angry if in fact I had decided to go to Queensland for treatment or knowing that I might need a transfusion to subsequently find that they had 70 per cent false negatives. Seventy per cent of the people who were given the surrogate testing in fact had the virus, but it was not identified by the testing. I think that it has to be stated clearly that the ARCBS did act on the best advice appropriate to Australia at the time. Senator McLucas has already given an explanation of what `appropriate to Australia' means.

Regarding those who are seeking compensation, the overwhelming majority want help with their management. The compensation systems that are available through the states and territories have in some cases not been made known to some of the sufferers, and I think they should be. The states and territories should be more upfront in saying that this compensation is available and allowing people to access it. When we look at the lack of understanding in the community, the discrimination by the community and sections of the medical community and allied professionals is something that we have to overcome. It is sad to see that people who have contracted it this way, through blood products, are firstly viewed as having contracted it through some other means. It all adds weight to the way in which we must educate the public to a far greater degree.

There is much more we could say, and I know my colleagues to follow will say more. In the limited time I have got, I want to put on the record my thanks to Senator McLucas for her excellent chairing of this inquiry under very difficult circumstances with very sad stories, to my colleagues on the inquiry and, of course, to the outstanding community affairs secretariat, whose praises I can never sing enough. To Elton Humphery and his team, thank you very much for all your assistance.

Senator HUTCHINS (New South Wales) (10.41 a.m.) —Last year I moved in the Senate that the terms of this inquiry be sent to the Senate Community Affairs References Committee. That was the result of an approach that was made to me by my very good friend and the former member for Dobell, Michael Lee. Michael asked me to speak to two men who had a particular problem with hepatitis. Like Senator McLucas, I was not all that aware of hepatitis. I did not realise there were five types of hepatitis, as I do now. I am sure my colleagues now know, as I do, a lot more about this disease, but I was not as sure about hepatitis C.

Michael asked me to see two men: Reverend Bill Crews, head of the Exodus Foundation, and a chap called Charles MacKenzie, head of the Tainted Blood Action Group. They put to me the tales that both Senator McLucas and Senator Knowles have detailed here today, tales of men and women—in particular women who have been through childbirth—who have had blood transfusions and who, as a result of those blood transfusions, have been infected with hepatitis C. I also heard of men and women who had had car accidents in the 1980s, had had blood transfusions and had been infected with hepatitis C. I also heard of people who had had elective surgery in that period, had also required blood transfusions and had been infected with hepatitis C. As a result of those approaches to me and the consent of my colleagues, both Labor and non-Labor, we put together the terms of reference for this inquiry.

You will see in the back of the report that I have made an additional statement. I did toy with the idea of making a minority report and, towards the end of my speech, I will come to why I did not. My concern about the development of this disease is in some ways in contrast to the emphasis that my colleagues have used in this report. I do not believe that the medical authorities who sat down in the 1980s acted out of any malice or greed, but I reckon that in the 1980s the men and women in the medical authorities in this country made the wrong decision. There was a test available for men and women who needed blood transfusions—a test that was inaccurate, as Senator Knowles has said, but available.

In 1981, the Americans identified a strain of hepatitis that they called non-A, non-B. In January 1981, they sat down and discussed how they might deal with this. Later in the year, once again they discussed how they should deal with this problem. In a hotchpotch fashion throughout the United States, a system called ALT testing was introduced. It was not totally accurate, but it was accurate enough—as Senator Knowles herself acknowledged in relation to what happened in Queensland—that maybe three out of 10 units that were tested were positive for hepatitis C and would not have been transfused into men and women who needed that blood transfusion. That is a fact. Throughout the 1980s, the blood authorities in this country—the state and federal authorities—grappled with that idea. They continually rejected the idea of ALT testing.

I understand the compassion my colleagues have expressed here this morning in relation to the decisions that were made. However, that is no comfort to the men and women who got this disease following childbirth, car accidents or elective surgery. Both Senator McLucas and Senator Knowles have spoken eloquently about the damaging effects this disease has had on men and women, particularly women. Their relationships are finished. From the 1980s, men and women have gone for many years wondering why they were lethargic, why they could not contribute to normal daily life and why they could not contribute to their jobs. These people lost their relationships—their husbands or their wives—and they lost their jobs.

This has all come about as a result of the infection that came into the blood system in the 1980s. As I said, at a meeting in Washington on 9 January the US authorities identified that this was a problem. On and off, as I said, from that period onwards there was a hotchpotch approach by them to the introduction of this testing. We need to move on from there. This has occurred; we need to deal with what is happening now.

I believe that the trust that men and women in this country put in the authorities proved to be fallible. As a member of parliament, I cannot for one moment look at those people and say that there was not a time when we could have acted differently and we did not. There was a time when we could have acted differently, and we did not. I do not blame the Red Cross in particular for this. In the end, the federal and state authorities were responsible for our blood supply. They sat down and made these decisions.

As late as 1987, once again the blood banks in this country met and said that they would not introduce this system. But by 1988, on the advice of Dr Catherine Hyland, the Queensland authorities did. Senator Knowles has mentioned the `success' where they identified three out of 10 or the `non-success' where they identified seven units out of 10 that were false—whichever you call it. It does not matter now. What matters now is the fact that we have done this inquiry and we have raised the level of public knowledge of what has occurred in this very despicable part of our medical history. I am not necessarily satisfied that the recommendations go as far as they should, but, thanks to my colleagues, I have had a significant input into revising some of them.

I want to talk about aspects of the compensation that has occurred in other parts of the world and what is happening now in Australia. In Ireland, there are lump sum payments at all stages of the disease; there is free medical care available; and tribunal decisions are based on the loss of earnings, health care costs and quality of life. In Canada, there are lump sum payments based on loss of income; there is free medical care for items not covered by public and private schemes; and there are incidental payments, monthly payments and compensation for dependants. In the United Kingdom, there are lump sum payments of 20,000, with another 25,000 for liver disease. In particular, there are special payments for those who have lost their medical files.

The recommendations in this report make reference to the look back program. It has proven to be inadequate and ineffective, but it is a good idea and it should be beefed up. As a result of our inquiry, we have found that the blood authorities and medical authorities in the various states have not had effective programs that allow us to identify where that blood came from and to whom it was transfused. In our inquiries, people made statements and submissions saying that they inadvertently and accidentally donated blood that was infected.

In the minute left to me, I want to say why I determined not to put in a minority report. Already in this country the state and federal authorities are contributing to compensation schemes for people who have suffered hepatitis C and continue to suffer it. Already the Commonwealth has contributed $7 million. The period between 1986 and 1990 seems to be the window for which these settlements are being made. Unfortunately, they are confidential. I did not put in a minority report because I think it is significant that the two government senators were prepared to sign up to a scheme that allowed for a fund to be set up to assist the men and women who suffer from this terrible disease. That is a significant step and I applaud them for it. One government senator has a long history of involvement in the social security and health area; one is a former Chief Minister for the ACT, where this scheme is already operating.

Senator HUMPHRIES (Australian Capital Territory) (10.51 a.m.) —The Senate Standing Committee on Community Affairs' inquiry into hepatitis C and the blood supply in Australia was certainly a matter that occasioned considerable concern among many people and great soul-searching among members of the committee that looked at this issue as we appreciated that a great medical and social problem evident in Australia had not been, in many respects, fully addressed and had certainly not been brought out into the open to the extent that was required, prior to this inquiry being held. It was important to examine those issues and look at the questions of whether adequate services and compensation were available to victims of hepatitis C in this country—people who in many cases had incurred that disease in circumstances that were entirely exculpatory for themselves. They should have been able to expect better while in the care of medical professionals, at whose hands they often, unfortunately, contracted this disease.

During this inquiry it became evident that hepatitis C and its effect on victims have not been fully understood. That is complicated by a number of factors. As members of the committee have mentioned, diagnosis of this disease is not always immediate; some people go for years before being diagnosed. In fact, many people incur the disease through blood transfusions in traumatic circumstances: in childbirth, as a result of a car accident and so on. Many sufferers are lumped together in the minds of other people with those who incur diseases such as hepatitis C through unsafe behaviours, such as intravenous drug use. Coupled with all of that, there is a general lack of public understanding of what hepatitis C is, how it affects you and how it can be contracted and passed on.

In all those circumstances, it was clear that more needed to be done. I am very pleased that, as Senator Hutchins indicated, the committee has taken the step of recommending a number of changes to the way in which authorities deal with the victims of hepatitis C infection and improve the services available to them and to their families.

A pivotal question the committee faced, however, was whether it was appropriate to attach blame to the agency or agencies primarily responsible for the transmission of hepatitis C infected blood. The Australian Red Cross Blood Service, of course, was a key witness before the inquiry, and its evidence was examined very carefully indeed. There is a propensity in our society to believe that we need to attach blame and that we need to find a person or party at fault when things go badly wrong. In the case of those infected with hepatitis C, things certainly did go badly wrong. The questions for us, however, were whether or not blame should be attached to the Red

Cross Blood Service or to another party or parties in this process, such as the Commonwealth Serum Laboratories, and to what extent we would judge their behaviour—in light of the challenge that was facing those organisations in the late 1980s—as having been reprehensible in some way.

At the end of the day, it is true that the committee felt that there was a great preponderance of evidence pointing in a number of directions at the one time, making it unsafe to conclude that, in particular, the Red Cross had behaved reprehensibly in choosing not to implement a system of surrogate testing in most places in Australia. Surrogate testing, as members have pointed out, was employed in some places in Australia and in some other places in the world, particularly in the United States. It is also true that it was not employed in many places around the world and in most states of Australia. The uncertainty of the effectiveness of that testing was the critical issue that we came to grips with.

There was an ambiguity of evidence—an inconsistency in the clarity of the evidence—about whether surrogate testing would or would not have effectively provided a tool to eliminate an appropriately high level of risk of infection from hepatitis C. The nature of the challenge which the Red Cross and others faced was best summarised by Professor McCaughan, who at length discussed the question of what evidence was available and how it should have been assessed by parties at the end of the 1980s. He cited the concept of equipoise whereby:

If on the balance of the evidence you do not know what to do, then either choice is ethically acceptable.

Clearly, the suppliers of blood and blood products in Australia at that time for the most part, with some exceptions, made the decision to continue to supply blood in those circumstances. The fact that they did so led to many people being infected. The part in the process that bodies such as the Red Cross played led to an apology to the people who were infected. I am very pleased that the Australian Red Cross has seen fit to take that step.

I think it is a mistake, however, to assume from that that there has been serious culpability on the part of players such as the Australian Red Cross in the way in which blood products were supplied. They were facing a difficult choice—a choice which, had any of us been facing it, we would have encountered exactly the same level of difficulty in resolving. I believe the many challenges which a body such as the Red Cross face in these circumstances need to be borne in mind when passing judgment many years later on their conduct, particularly where it has led to such devastating consequences.

A factor taken into account at the time—and rightly so, in my opinion—was that a testing regime, such as surrogate testing, would have led to a very high number of false negatives, as Senator Knowles has suggested. That would have had a serious downside for other people—people other than those who might have become infected ultimately by such diseases as hepatitis C—in the loss of many valuable and suitable donations to Red Cross services around Australia. Evidence brought before the committee was that, even in Queensland, there were significant problems with loss of donors and finding replacement donors for those who were being rejected—for the most part, falsely—because the testing suggested that they were not suitable donors when in most cases, in fact, they would have been. If that problem had been replicated across the whole of Australia, over potentially a longer period than the window during which surrogate testing was the only means of identifying suspect blood, our health services and our blood transfusion services would have faced a real and a very significant crisis.

I believe, with the enormously beneficial capacity of hindsight, that it was appropriate to protect the whole of the blood supply and the capacity of people generally to access blood products when they needed them, particularly in traumatic or critical circumstances. I believe that the decision made by Red Cross in states other than Queensland was appropriate. That does not mean to say that it was inappropriate in Queensland. I believe that is not a conclusion you can draw from that statement. As Professor McCaughan put to the committee, given the ambiguity of evidence and the lack of any clear indication one way or the other, either choice was ethically acceptable. I also wish to thank the other members of the committee and the staff of the committee for the help they provided to us in this very difficult but extremely important inquiry.

Senator LEES (South Australia) (11.01 a.m.) —I would like to begin by thanking the secretariat of the Community Affairs References Committee. I particularly thank the other members of the committee. I believe all of us, government and non-government senators, set out with the aim of getting a result. We put aside any party affiliations and worked to see if we could get some real support and assistance for those people who are now facing life with a devastating disease that affects not only them and their relationships but also their families. So I put on the record my thanks to everyone who was involved in the committee.

I also thank those people who were prepared to come before us and share a very personal part of their lives. Many people, obviously, have been affected in absolutely every way possible, from their opportunities to have a family, because of the risks of passing on the disease to children, to their employment. All sorts of opportunities have passed them by. They are not able to take part in sport or any activity that requires stamina and endurance. So I thank those people who put all of that aside and were prepared to relive their experiences for the committee to help us understand what it is like to be hepatitis C positive.

I would also like to thank the Red Cross. Obviously the committee does not want to do anything—indeed we did not do anything—that would in any way put at risk the future blood supply by discouraging people from donating. As a donor, I know all the extra procedures that the Red Cross has put in place over the last year or so. We all have our own cards now that have to be scanned as we donate. I acknowledge the frank and open evidence of the Red Cross before the committee and the way they have worked to make sure that these types of devastating mistakes do not occur in the future.

I was aware of hepatitis C and how virulent it was, but I was not aware of how many people had been infected by tainted blood throughout the 1980s and 1990s. I was certainly not aware of the effect this was having on so many in our community. All of us on the committee—and here I particularly commend Senator Hutchins for his passion on this issue and for bringing it to our attention—wanted a result. We wanted to work for what would actually make a difference to the lives of the people who are out there having to deal with hepatitis C on a daily basis. Hopefully, the government will now respond positively to our recommendations. Perhaps recommendation 6, dealing with the way the committee is set up, is the most important. We must do the Lookback program properly and then make sure that the necessary service delivery, the support, the day-to-day counselling, the medical help, the welfare services et cetera are provided for people battling hepatitis C. Some of it is covered under Medicare, but an awful lot of things are not covered: transport, alternative medications, non-prescription items and a whole raft of issues for families, such as counselling and support.

Hopefully, the government will rapidly accept the final recommendations and, before we go into the usual hiatus at election time, respond to the committee report, which is unanimous. That is unusual for references committees, unfortunately. The government should now move on and do two things: firstly, respond to the specific recommendations and help those people who are battling hepatitis C and, secondly, with the states look at better prevention measures across the board. Whatever way hepatitis C is transmitted, we need to stop it. We need to reduce, if not eliminate, the passing on of hepatitis C. From improving the Lookback program and supporting the Red Cross as it further secures Australia's blood supply, so nothing like this can be passed on in the future, to needle exchanges and education campaigns—it all has to be put in place so that no Australian in the future contracts this terrible disease. I close by again saying thanks to all those people who are hepatitis C positive who came before the committee and shared their experiences with us.

Senator MOORE (Queensland) (11.06 a.m.) —I add my voice to those of the other senators who shared in the experience of the hepatitis C inquiry by the Community Affairs References Committee. None of us who participated in this inquiry in any way remained unaffected by this experience. We learnt a lot about hepatitis C. Many of us did not have that knowledge before we started this activity. We learnt a lot about the history and various causes of the condition. Amazingly detailed medical evidence was presented to the inquiry as to how this condition could be acquired and how, throughout the 1970s and 1980s, across the world people were struggling to identify this particular strain of the very serious disease of hepatitis. We learnt a lot about the medical causes. We learnt a lot about the science. But, for many of us, I think the real experience of this inquiry was to learn about the effects of hepatitis C.

No-one could remain untouched by the stories of the people who came before our inquiry who had acquired this disease through a range of different ways. All of the other senators on the committee have mentioned the different experiences of the people who came before us. We also heard from their families, from their carers and from their friends. They were all sharing the pain. The pain was not just in finding out that they were ill. In many cases, the pain was in being ill for years and in not understanding why they were not able to relate to their families, why they were not able to work effectively in their businesses and why their friends were not able to relate to them anymore because they were not the same person. I will always remember the woman who sat in front of us and said she did not know herself anymore; she used to be someone different. She said that 10 or 11 years ago she had lost herself. One lesson out of this inquiry is that we as a community must help all of those people refind themselves so they no feel longer isolated or afraid due to the condition we now know as hep C.

Another lesson from this inquiry is that organisations must be able to keep better records. I was amazed to hear how people learnt about this condition in the seventies and eighties. People were in hospital, people were seeing doctors, people were donating blood and when we tried to find clear evidence from that time from the doctors, from the hospitals and from the blood banks it was not all available. We heard about the Lookback program. We all know that it is not working. We know that it must work better because people have a right to know their medical histories and to find out the cause of their condition, if that can be discovered. The Lookback program has not been able to enable them to do that because of the complexity and the interrelationship of the different record-keeping systems across the country. In 2004 that is something we must learn. That kind of complexity and confusion must be addressed. We as citizens have the right to know our medical histories and to be able to trace them. I do not know how far we can go back, but we should be able to say that from 2004 records about us should be accurate.

Another clear lesson from this process is that there must be understanding and better support from the medical services. I was amazed to hear that some of the worst cases of discrimination against people who had hepatitis C were perpetrated by people in the medical profession. This came out particularly in New South Wales but not only in New South Wales. There seems to be a significant lack of effectively trained and sensitive people across the range of medical professions who can provide the immediate medical help and the personal support the patients need not only at the time of identification but through the whole process of their condition—and not just for the patients themselves but also for their families. As Senator Hutchins said, we heard very sad cases of where families had been destroyed by this condition, of where people had lost their families as well as themselves. These groups in our community need sensitive support and counselling, not just immediately and not just for a short time but into the future. This counselling should be done in such a way that it is flexible, so people can access it when they need it without too many barriers or obstacles. That must be one lesson we learn from this process.

We should have an education campaign for the wider community. In one hearing someone said to me that, if one thing could be achieved out of our inquiry, it would be an effective across-the-board education program so that people could understand what this condition is all about, the various ways in which it can be acquired and that people who have it are living beside us on a daily basis and are not somehow unclean or not able to be communicated with. Over and over again we heard that people who had hep C felt that they had been rejected by their community, that somehow they no longer had a role to play in the community, that they had been isolated and that in many ways they felt betrayed. An education program is not just something in a paper; it is not just a sign in a doctor's office. In this day and age in 2004 there is a wide range of education programs available. We should be able to come up with something that actually works. It is important that, when we are developing these programs, we involve the people with the knowledge. The people who came to our inquiry have the knowledge. They have had the pain, they have had the experience and, moreover, they have had the courage to say: `Look at me. I have this condition and I am here. Learn from me, and we can grow together in a community and be stronger and better.'

We heard during the inquiry that some had acquired the condition. We heard that some wonderful people and organisations had set up support groups to work with the community. The Tainted Blood Product Action Group in New South Wales has done amazing work to get people to connect with each other and to understand and feel as though they have a right to be heard. We also heard from people from the various medical professions and from the Australian Red Cross. There was goodwill around our inquiry. People wanted to find a way forward. But the sad thing was that up until this inquiry they seemed not to have been talking to each other. People had been isolated not only by their condition but also by the people with whom they needed to communicate. They had felt rejected and there was a wide gap through which there did not seem to be any way of communicating. If people could just listen to each other instead of closing their minds and their hearts to what people are saying, we would actually know where to go after the inquiry. I think that has been achieved in some way, because I do believe that this inquiry at least got the various groups talking to one another without immediately going into battle lines.

There must be acceptance in the process that follows that there is not a typical person with hepatitis C. Everybody has different needs and everybody has different expectations of where we should go next, but one thing this Senate inquiry has done is to let the community know that they have a right to be heard, that this is an issue that must be talked about publicly and that people should not be labelled and isolated because of a medical condition that they have acquired. I hope that the lessons that we have learnt from this inquiry are that there is no-one in the community that needs to be totally isolated, that we have opportunities to work together and that we have opportunities to learn and move forward. That is not to stop any litigation or process that is going on—because everyone has a right to that as well—but we must be able to do what the spokesperson from the Red Cross said:

What we would now like to focus on is the present and the future and we would like to discuss with you today how we are able to move forward beyond the Senate inquiry.

We are keen to work together, we are keen to listen to each other and, somehow through all of this, the Senate inquiry will have done its job and we will have awareness and some way forward so that hepatitis C is known, understood and supported. I seek leave to continue my remarks later.