Annual Report

2001

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1 Preface

Since this is my last year as Chairperson of Alzheimer Europe, I wanted to take the opportunity of this Annual Report to briefly look back over the past five years and to highlight some of the changes, which the organisation has undergone.

The organisation has grown considerably in membership, in its activities and also on a financial level. Thus Alzheimer Europe now counts 31 member organisations in 26 European countries, with 10 new organisations having joined the association in the past five years.

Equally, the number of projects carried out in this time is truly impressive. Our Care Manual and Children's book have been published in seven languages and have helped our organisations in providing relevant information to carers and grandchildren of people with dementia. For the first time, an organisation carried out an inventory of all legislation affecting the daily lives of people with dementia, thus allowing a comprehensive comparison of how the legal rights of people with dementia are respected in the member countries of the European Union.

Apart from these very useful services for its member organisations, Alzheimer Europe has also taken on a life of its own. As a privileged partner of the European institutions and a consultative organisation of the Council of Europe, the association has been called upon to develop consensual positions on behalf of its member organisation and to defend the interests of people with dementia and their carers towards these European bodies.

From a financial point of view, the organisation has also grown considerably. In 1995, the organisation had an annual income of some 15,000 EUR, which resulted exclusively from the fees of the member organisations. This year, Alzheimer Europe had an income of over 500,000 EUR from a variety of sources, such as European subsidies, corporate sponsorship, donations or the sales of our publications.

Looking back therefore, I would like to thank the dedicated staff of Alzheimer Europe as well as the contributions by our Board members and all our member organisation who made this development possible. From a financial point of view, I would also like to thank Aventis, Janssen-Cilag and Pfizer for their continued support, as well as the Luxembourg Association and through them the Luxembourg Ministry for Family. Without their support, Alzheimer Europe would not have been able to look back on such a successful year.

I am confident that the growth of Alzheimer Europe will continue in the coming years and I am particularly happy that in 2001 we started the development of a new business plan which will set out new and clear priorities for the future work of the organisation.

But 2001 was not only the year when we discussed the future direction of Alzheimer Europe. We were again very successful in carrying out a European project, Equality in the Provision of Care at Home (EPOCH), which provided us with useful information about the different needs and expectations of male and female carers of people with dementia.

We continued to be a voice for people with dementia and their carers by developing consensual positions on the participation of people with dementia in clinical trials and in research, as well as on the use of genetic test results by the insurance industry.

Alzheimer Europe is now a recognised player and our involvement and contribution to the development of the European Federation of Neurological Associations or the creation of a European Patients' Forum show how far the organisation has come.

In 2001, we were also greatly honoured that H.M. Queen Silvia of Sweden accepted the very first award created by Alzheimer Europe for outstanding services for people with dementia and their carers. The ceremony in which Britt Ekland presented the award to H.M. Queen Silvia was most definitely a highlight of last year's activities. In her acceptance speech, H.M. Queen Silvia shared her personal experience of caring for a loved one with Alzheimer's disease with us. Her dedication and her contributions to the work of Alzheimer associations in Sweden and throughout Europe serve as an example to all of us.

I am therefore fully confident that Alzheimer Europe will continue to grow and develop and I wish the new Chairperson and Board of the organisation continued success.

Jeannot Krecké

Chairperson

2 Alzheimer Europe's European Projects

Due to a discontinuation of funding of specific projects for "people suffering from neurodegenerative diseases" by the European Commission, Alzheimer Europe was unable to secure funding on a European level in 2001. Nevertheless, the organisation finalised its work on its project on equality in the provision of care at home, which was funded under the European programme for measures to achieve equality between men and women and continued the dissemination of the results of previous European projects.

2.1 Equality in the Provision of Care at Home (EPOCH)

Alzheimer Europe received funding from the Social Affairs and Employment DG of the European Commission to investigate the gender imbalance related to the task of caring for someone with dementia.

The project was carried out in close collaboration with participants from our member organisations in Belgium, Denmark, Germany, Iceland, Ireland, Italy, Luxembourg, Norway and Spain, as well as with the help from women's expert Viviane Ecker from Luxembourg.

An extensive survey was developed and answered by 585 carers in the participating countries. The survey aimed at discovering in how far factors such as availability, perceived suitability, willingness, social pressure, support from others and sense of duty influence people to take on the task of caring.

The filled in questionnaires were evaluated in 2001 and at the same time, the organisation carried out an intensive literature search in the field and aimed at identifying good practices in the countries covered by the project.

The findings of the survey, a list of good practices, as well as the resulting recommendations were published in a report which was published in 2001 and which can be ordered from the organisation.

2.2 Dissemination of previous European projects

In 2001, the organisation also continued its work in disseminating the results of previous European projects.

In particular, thanks to the collaboration between the French-speaking member organisations of Alzheimer Europe (France, Belgium, Luxembourg and Switzerland), the organisation was able to produce the French edition of the Care Manual. This publication provides practical tips for carers

of people with dementia, general information on Alzheimer's disease and other forms of dementia, as well as information on legal and social help that is available in the four countries. With this edition, the Care Manual developed by Alzheimer Europe has now been published in 7 languages, namely Danish, French, German, Greek, Italian, Portuguese and Turkish.

The Luxembourg Ministry of Education again supported the publication of our Children's book and some 5,000 copies of the German edition were distributed to and used by ten-year-old school children. Furthermore, the Danish, Flemish and Portuguese editions of the Care Manual were also published in 2001, thus bringing the number of languages in which the Children's book is now available to 7 (Danish, Flemish, French, German, Greek, Italian and Portuguese).

Finally, in 2001 the organisation disseminated the recommendations on the legal rights of people with dementia, which can be ordered in one of the official languages of the European Union from the Alzheimer Europe secretariat.

3 European Developments

As in previous years, Alzheimer Europe further developed its relationships with the European institutions (Commission and Parliament), as well as with the Council of Europe. More and more, the organisation was called upon to comment on proposed legislation by the European institutions or on draft protocols of the Council of Europe. The organisation was able to strengthen its public affairs role thanks to continued funding from pharmaceutical companies (Aventis, Janssen-Cilag and Pfizer).

3.1 European Union

A number of legislative proposals and discussions within the European institutions proved relevant to Alzheimer Europe and the organisation actively developed position papers which reflected a consensual approach of its member organisations to the issues under consideration.

3.1.1 Public Health Programme

Throughout 2001, the European Parliament, the Commission and the Council of Ministers discussed the adoption of the new public health framework programme of the European Union. Together with its member organisations, Alzheimer Europe launched a letter writing campaign to members of the European Parliament stressing the importance of addressing the problem of growing numbers of people affected by neurodegenerative diseases and in particular Alzheimer's disease.

The organisation was therefore heartened by the decision of the Environment and Public Health Committee of the European Parliament to include neurodegenerative diseases amongst the priority areas that the new framework programme should address. Unfortunately, these positive amendments were not retained by the Commission and Council of Ministers.

At the second reading 12 December 2001, the European Parliament adopted the public health programme. Alzheimer Europe regretted that no majority was found for an amendment, which would have allowed European public health organisations to be funded through the programme, but nevertheless welcomed the possibility for European NGOs to have specific projects funded by the programme.

3.1.2 Equality of Access to Care and Treatment

In order to raise the profile of Alzheimer Europe and the awareness of the relevance of dementia among the Members of the European Parliament, the association organised a third Forum on equality of access to care and treatment on 17 March 2001.

This public event in the European Parliament in Brussels aimed at highlighting the existing divergences between European countries when it comes to access to care and treatment for people with dementia. Apart from focusing on the differences in service provision and availability of treatment options, the forum also looked at varying attitudes in addressing the needs of specific groups of carers, such as male carers, carers of younger people with dementia, gay and lesbian carers and carers from ethnic minorities.

The proceedings of this event were published in 2001 and are available from the Alzheimer Europe secretariat. Alzheimer Europe is particularly grateful to the companies, which helped to finance this important event, as well as to Karla Peijs, MEP for her invaluable support in organising this event in the European Parliament.

3.1.3 Clinical Trials

The European Parliament discussed the adoption of the clinical trials directive in 2000 and 2001. Alzheimer Europe was closely following the discussions, as the participation of people unable to consent was also covered in the directive.

Since the Environment and Public Health Committee of the European Parliament adopted specific amendments to address this issue, Alzheimer Europe felt obliged to consult its member organisations on an issue of great importance to people with dementia.

The consultation of member organisations allowed the Board of Alzheimer Europe to develop a consensual position which supported the amendments of the European Parliament, in clearly limiting the participation of people unable to consent to those clinical trials where these may expect a direct benefit for their situation.

Alzheimer Europe was also grateful to Dr. Peter Liese, the rapporteur of the clinical trials directive for attending the Alzheimer Europe Forum on 7 March 2001 and presenting the views of the European Parliament to the assembled members of the organisation.

The position paper on the participation of people with dementia in clinical trials is annexed to this Annual Report.

3.1.4 Genetics

Alzheimer Europe also closely followed the work of the Temporary Committee on Human Genetics of the European Parliament, as a number of issues such as genetic testing and stem cell research are also of importance to people with dementia.

As a result, Alzheimer Europe launched a consultation process amongst its members to develop a position on both genetic testing and stem cell research. While a consensus was quickly found for our position on genetic testing, this was not the case for stem cell research and a position on this subject should be developed in 2002.

In its position on genetic testing, the organisation argues against the use of genetic test results by the insurance sector and by employers, as the use of such results is currently unjustifiable and premature. In the opinion of Alzheimer Europe, such use of test results would lead to further social exclusion of people with dementia and their carers. Furthermore, the eventual use of genetic test material by the insurance industry might deter people from actually taking genetic tests or participating in genetic research.

On 5 November 2001, Alzheimer Europe presented its position to Mr. Robert Goebbels, MEP, the Chairperson of the Temporary Committee on Human Genetics. Furthermore, the association

organised a public forum on the “Genetics of Alzheimer’s disease” on 17 December 2001 in the European Parliament.

The position paper on genetic testing can be found as an annex in this Annual Report.

3.2 Council of Europe

Alzheimer Europe enjoys consultative status with the Council of Europe and participated actively in the quarterly NGO meetings, which were held in Strasbourg and in particular the “Health” sub-grouping. At the same time, Alzheimer Europe became involved in specific working groups set up by other NGOs with consultative status and developed a response to the Draft Additional Protocol on Biomedical Research.

3.2.1 Palliative care

Alzheimer Europe became active in the ad hoc working group on palliative care at home. Issues such as obstacles to maintaining a terminally ill person at home, how to avoid exhaustion of family carers, the efficacy of palliative care networks and reasons for readmission to hospital were considered relevant.

To study these questions, a questionnaire targeted at general practitioners was devised, based on the questionnaire, which had already been successfully piloted by the European Association for Palliative Care (EAPC) in the Strasbourg area of France.

Alzheimer Europe and some of its member organisations assisted in the ad hoc distribution of questionnaires to general practitioners. The organisation also put the questionnaire on its Internet site. The responses received were forwarded to the EAPC for evaluation.

3.2.2 Psychotherapy and human rights

In 2000, the Council of Europe produced a White Paper on the “protection of the human rights and dignity of people suffering from mental disorder, especially those placed as involuntary patients in a psychiatric establishment.” This document was fairly extensive in that it covered mental disorders in general, as well as internment on civil as well as criminal grounds and Alzheimer Europe was one of the organisations, which responded to the consultation document.

In 2001, the European Association for Psychotherapy wanted to further examine some of the questions of the white paper and particularly the issue of access to psychotherapeutic treatment. An ad hoc interdisciplinary group was therefore set up in which Alzheimer Europe has agreed to collaborate.

3.2.3 Additional Protocol on Biomedical Research

In 2001, the Steering Committee on Bioethics (CDBI) of the Council of Europe finalised its Draft Additional Protocol to the Convention on Human Rights, on Biomedical Research and declassified the document for consultation purposes.

Alzheimer Europe received the document and was asked to comment. The organisation therefore developed a position paper on the issue of the participation of people with dementia in research, which was adopted by the Board of Alzheimer Europe on 16 December 2001 and forwarded to the services responsible within the Council of Europe.

4 Networking

As in previous years, Alzheimer Europe continued the development of closer links with other organisations active on a European level. We were particularly encouraged by the growing co-operation between researchers in the framework of the European Alzheimer's Disease Consortium and their desire to co-operate more closely with Alzheimer Europe. Furthermore, Alzheimer Europe took part in various activities organised by the European Federation of Neurological Societies (EFNS) and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

4.1 European Alzheimer's Disease Consortium (EADC)

In 2001, a number of researchers active in the field of Alzheimer's disease examined ways of co-operating more closely on a European level and created the European Alzheimer's Disease Consortium. Under the leadership of Prof. Bruno Vellas from Toulouse (France) and Prof. Bengt Winblad from the Karolinska Institute in Stockholm (Sweden), these researchers decided on some priority areas for research in Europe and examined the possibility of securing funding under the Research and Development Framework Programme of the European Union.

Alzheimer Europe has been closely associated with these centres and will be included as a member in a number of projects that the EADC is hoping to develop in 2002. Alzheimer Europe has also developed and will continue to maintain the Internet site of the EADC.

4.2 European Federation of Neurological Associations (EFNA)

Alzheimer Europe has been among the founding members of the European Federation of Neurological Associations, an organisation aiming at improving the quality of life of those affected by neurological disorders. At its second Annual General Meeting in London, Jean Georges, the Executive Director of Alzheimer Europe was elected to the EFNA Board.

EFNA was officially launched and presented in the European Parliament, thus further raising the visibility of people living with neurological disorders. Commissioner Byrne and a number of supportive Members of the European Parliament were present at this official launch on 23 October 2001 in Strasbourg.

4.3 European Patients' Forum

Aware of the growing number of political developments on a European level, which may directly impact on the lives of patients, a number of patient organisations met on several occasions in order to discuss how best to strengthen the voice of patients on a European level. Alzheimer Europe has been among the organisation, which discussed the possibility of creating a European Patients' Forum, which would aim at exchanging information between patient organisations on relevant European developments and which should ultimately become an important partner for European institutions for consultation purposes.

Though the Forum has not been formally launched, a number of organisations have agreed to work more closely together and in 2002, Alzheimer Europe will continue to work towards the establishment of an independent and inclusive Patients' Forum.

5 Other activities

5.1 Annual Conference: "Across the old borders"

The 11th Alzheimer Europe Conference "Across the old borders" took place in Bucharest (Romania) from 9 to 12 June 2001. The conference was an ideal opportunity for the over 500

participants to exchange information and experiences and to raise the profile of this disease in Romania.

Not only did the conference bring together delegates from across a once-divided continent, but also representatives from various professional backgrounds, from carers of people with dementia and people involved in Alzheimer associations to nurses, professional carers and medical professionals involved in the care and treatment of people with dementia.

The success of the meeting was greatly due to the organisational skills and dedication of the members of the Romanian Alzheimer's Society and we would like to take this occasion to pay special tribute to them.

5.2 Alzheimer Europe Award

In 2001, Alzheimer Europe for the first time presented the "Alzheimer Europe Award for outstanding services for people with dementia". We were particularly honoured that H.M. Queen Silvia accepted the award, which was presented to her by Britt Ekland in the framework of the Alzheimer Europe Forum in the European Parliament on 7 March 2001.

With this award, Alzheimer Europe wanted to honour the contributions of H.M. Queen Silvia to raising the awareness of dementia in Sweden and throughout Europe by speaking about her own personal experience of caring for a loved one with Alzheimer's disease, by supporting the work of the Swedish Alzheimer's associations and by founding a special training programme for nurses specialised in the dementia field.

5.3 A new communication strategy

Alzheimer Europe further developed its communication strategy between its member organisations, other European organisations and the European institutions. Although the organisation had to discontinue the publication of its quarterly newsletter due to funding problems, Alzheimer Europe was able to replace it with monthly e-mail updates.

These proved more efficient in informing over 1,000 interested individuals about the activities of Alzheimer Europe, as well as other relevant European developments. Furthermore, thanks to a very generous initiative by Weber Shandwick Adamson, Alzheimer Europe receives all relevant articles on Alzheimer's disease published in a number of European newspapers and journals and is thus able to provide the readers of the updates with interesting research information.

In 2001, Alzheimer Europe also completely revised its Internet site. All information and documents produced by the organisation are now all available on the Alzheimer Europe Internet site, which is updated on a regular basis with news about the activities of the organisation. The new strategy has led to increased traffic to the Internet site, which is now visited by between 4,000 and 5,000 visitors a week.

5.4 Towards a business plan for the organisation

In 2001, Alzheimer Europe also discussed the necessity for the organisation to develop a new business plan. This decision was taken by the Board and as an initial step, the organisation carried out a survey amongst its member organisations on their levels of satisfaction with the activities and publications of Alzheimer Europe, as well as their expectations about new activities of the organisation.

The findings of this survey were presented at the Annual General Meeting in Bucharest, which established a working group consisting of Ad Adriaansen, Harry Cayton, Jean Georges and

Pekka Laine with Jacques Selmes as Chairperson. The group started its work in 2001 and a new business plan for Alzheimer Europe should be adopted in 2002.

6 Financial Report

6.1 Report of the independent auditor

WILL BE DISTRIBUTED AT AGM

6.2 Balance sheet as of 31 December 2001

	2001 (Euro)	2000 (Euro)
ASSETS		
Current assets		
Debtors	38,426	4,820
Subsidies due (EC)	36,000	30,000
Cash at bank and on deposit	50,029	134,856
	124,455	169,676
Accruals	80	
	124,535	**169,676**
LIABILITIES		
Capital and reserves		
Results brought forward	62,017	59,833
Result of the year	9,041	2,184
	71,058	62,017
Creditors		
Payments received on account	32,982	33,175
Trade creditors	19,012	73,068
Other liabilities	1,483	1,416
	53,477	107,659
Accruals		
	124,535	**169,676**

6.3 Profit and loss account - Year ended December 31, 2001

		2001 (Euro)	2000 (Euro)
Support and revenue			
Subsidies from the EC		90,000	196,143
Other operating income			
Sponsorship		91,345	125,402
Sponsorship received on account		33,175	-33,175
Co-financing - ALA		80,282	56,123
Membership fees		44,500	22,200
Donations		9,753	15,481
Co-financing - Other		42,000	11,400
Publication sales and royalties		102,458	2,663
Internet services		1,575	1,487
Project participation		10,000	
AE Conference		5,000	
Other operating revenue		4,369	17,066
External charges			
Publication and Information material	-	90,445	-64,659
Travel expenses	-	37,693	-40,088
Communication costs	-	24,124	-34,958
Accommodation expenses	-	19,830	-27,974
Office rent and associated costs	-	19,340	-19,521
Interpretation/Translation	-	1,881	-8,594
Office stationery and related costs	-	9,681	-9,614
Leasing	-	4,705	-2,282
Membership fees	-	845	-1,303
Other costs	-	3,094	-1,208
Alzheimer Europe Award	-	4,878	
Staff costs			
Wages and salaries	-	100,671	-141,148
Social security costs	-	26,888	-38,157
Fees - Experts	-	162,483	-24,700
Interest receivable and similar income		2,629	2,240
Interest payable and similar charges	-	1,487	-640
		9,041	2,184
Income		517,086	417,030
Expenses	-	508,045	- 414,846

6.4 Acknowledgements

Alzheimer Europe would like to thanks the following individuals, organisations and companies for their invaluable financial support in 2001.

Platinum donors and sponsors (Donations and sponsorship from 50,000€)

European Commission (EU)

Association Luxembourg Alzheimer (L)

Ministère de la Famille, de la Solidarité Sociale et de la Jeunesse (L)

Gold donors and sponsors (Donations and sponsorship between 20,000€ and 49,999€)

Aventis (USA)

Janssen-Cilag (B)

Pfizer Europe (B)

Silver donors and sponsors (Donations and sponsorship between 5,000€ and 19,999€)

Lundbeck (DK)

Bronze donors and sponsors (Donations and sponsorship between 100€ and 4,999€)

Artesia Bank (L)

Bank of Bermuda (L)

Banque et Caisse d'Epargne de l'Etat (L)

Banque européenne d'investissement (L)

Banque Générale à Luxembourg (L)

Chandler Chicco Agency (UK)

Dexia-Banque Internationale à Luxembourg (L)

Société européenne de banque (L)

Zurich Assurances (L)

7 Annex I: Position paper on the participation of people with dementia in clinical trials

Executive Summary

1. The present paper constitutes the input of Alzheimer Europe and its member organisations to the ongoing discussions about the Clinical Trials Directive of the European Union.

2. It does not constitute a general position on the participation of people with dementia in other kinds of research, even if some of the following comments would be equally valid for such a position paper. A position paper on the participation of people with dementia in other kinds of research will be published shortly.

3. Alzheimer Europe would like to recall some general principles which guide this present response:

   a) A diagnosis of dementia does not in itself constitute a lack of legal capacity.

   b) An early and accurate diagnosis of dementia is essential and people with dementia have a right to be informed about their diagnosis.

   c) People with dementia should be encouraged to write advance directives regarding important decisions in case they become incapacitated.

   d) National governments should put into place legislation recognising the legally binding character of advance directives.

   e) Informed written consent has to be given by the person with dementia or his/her legal representative for important treatment decisions.

4. On the basis of these principles, Alzheimer Europe has developed the following position with regard to the participation of people with dementia in clinical trials:

   a) In the early stages of their disease, people with dementia can themselves consent to clinical trials or declare their willingness to participate in clinical trials in an advance directive.

   b) Legal representatives should be able to consent on behalf of people with dementia to participate in clinical trials, if the following main conditions are met:

      i. the potential direct benefit for the person's health is clearly greater than the possible risks;

      ii. the risk of causing discomfort or distress is minimal;

      iii. the research has been approved by an independent ethics committee;

      iv. the same results could not be obtained with other subjects.

5. Alzheimer Europe requests further information on the participation of people with dementia in Phase I drug trials and the use of the concept of "direct benefit" in placebo trials and wants to encourage an ongoing dialogue between political decision makers, patients' and carers' organisations, the pharmaceutical industry and researchers on this subject.

6. Based on its current information, Alzheimer Europe does not endorse the participation of people with dementia in clinical trials WITHOUT a potential direct benefit for the participants. Nevertheless it reserves the right to re-consider its current position after receiving further information from the scientific community and the pharmaceutical industry with regard to the kinds of research that would be covered by this definition.

Introduction

7. Clinical trials are extremely important if the treatment of people with dementia is to be improved, as well as for the development of preventative measures and ultimately a cure. The participation of people with dementia in clinical trials is therefore necessary, yet it is equally clear that our approach to this question

has to be dictated by the respect for fundamental human rights, such as the right to self determination, the freedom of the individual and the integrity of the human body.

8. Alzheimer Europe has looked at this question in the framework of two successive projects, the first[1] consisting of an inventory of legislation affecting people with dementia in all the Member States of the European Union and the second[2] which involved the drafting of recommendations on how to improve the legal protection and rights of people with incapacity due to dementia.

9. The present discussion paper outlines some of the recommendations of Alzheimer Europe and its member organisations and raises some points, which deserve further clarification and discussion.

The necessity for a response by Alzheimer Europe

10. Over the past years, the issue of the participation of people with dementia in research has become an increasingly debated topic. Some European countries have already developed legal instruments defining the conditions under which people with dementia may participate in research.

11. These legal provisions differ from one country to another, yet some attempts have been made on a European level to harmonize these rules, most importantly the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine of the Council of Europe[3] and the Directive on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use[4].

12. In order for the voice of people with dementia and their carers to be represented in the ongoing discussions, Alzheimer Europe has developed the present Position Paper.

General principles

13. At its Annual General Meeting in Munich on 15 October 2000, Alzheimer Europe adopted recommendations on how to improve the legal rights and protection of adults with incapacity due to dementia. These recommendations obviously need to guide any response of the organisation regarding the participation of people with dementia in clinical trials.

14. Alzheimer's disease and other forms of dementia are progressive disorders, which may result in a gradual deterioration of a person's ability to function and a subsequent loss of a person's capacity to communicate or make important decisions regarding his/her life.

15. Yet, a diagnosis of dementia does not in itself constitute a loss of the capacity to take such decisions. Thus, the earlier a diagnosis of dementia can be made, the longer a person will be able to participate fully in decisions affecting his/her life.

16. Equally, in order to safeguard people's rights to self determination, it is essential to guarantee that every person diagnosed with dementia has a right to be informed of the diagnosis.

17. Furthermore, Alzheimer Europe would like to encourage newly diagnosed people with dementia to consider drafting advance directives in which they set out their future wishes regarding the conduct of their lives in case they become incapacitated and hence no longer able to take such decisions.

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[1] Financed with the support of the European Commission in the framework of their programme of "Actions in favour of people suffering from neuro-degenerative disease, more particularly Alzheimer type (DAT) and related disorders, and their (informal) carers" (SOC 97 201298 05F03)

[2] Financed under the programme of the European Commission of "Support for transnational actions aimed at combating discrimination against elderly and/or disabled people" (VS/1999/022)

[3] Hereafter referred to as the European Convention on Human Rights and Biomedicine (see Annex 1 for relevant texts)

[4] Hereafter referred to as the Clinical Trials Directive (see Annex 2 for relevant texts)

18. Alzheimer Europe campaigns for these advance directives to be legally binding and calls upon national governments to put into place the necessary legislation.

19. Informed written consent should be sought for important treatment decisions. In case, the person concerned is no longer able to give such consent, a legal representative should be able to do so on his/her behalf, provided that he/she has taken into account the previously expressed wishes of the person.

Participation in clinical trials

20. The general principles described in the previous section, dictate Alzheimer Europe's response to the question of participation of people with dementia in clinical trials.

21. Alzheimer Europe would like to draw a distinction between various situations that might arise when people with dementia are asked to participate in clinical trials. Thus, it is important to differentiate, whether people with dementia

    a) are able to give informed consent

    b) are unable to give consent, but have expressed their wishes in an advance directive

    c) are unable to give consent and have not previously expressed their wishes.

Informed consent

22. As previously mentioned, a diagnosis of dementia does not imply an automatic loss of the person's capacity to take important decisions, such as taking part in clinical trials.

23. A great number of people with dementia in the early stages of the disease will be able to fully understand the implications of taking part in clinical trials and should therefore be able to give their informed consent.

24. Nevertheless, since the loss of capacity is gradual, it might be appropriate in certain circumstances for the treating doctor to be consulted before the clinical trial can go ahead.

Advance directives

25. People with dementia may have expressed their wishes in an advance directive before the onset or in the early stages of their disease. Participation in clinical trials may be an issue that was expressly included in such an advance directive.

26. In such cases, wishes expressed in an advance directive can be considered as consent to participation in clinical trials. All restrictions or limitations, as to the fields of research that the person is willing to participate in, shall be fully respected.

Absence of consent or advance directives

27. This question has been discussed controversially by the member organisations of Alzheimer Europe and while a consensus could be reached on certain points, further clarification is needed before the organisation is willing to commit itself fully.

28. The following principles found unanimous agreement from all member organisations in order for a legal representative to give his/her consent to a person's participation in clinical trials:

    a) the potential direct benefit for the person's health is clearly greater than the possible risks;

    b) the risk of causing discomfort or distress is minimal;

    c) the research has been approved by an independent ethics committee;

    d) the same results could not be obtained with other subjects,

e) the legal representative has been specifically authorised to give consent by a court or by the person with dementia him/herself;

f) the interests and the wellbeing of the adult with incapacity are always placed ahead of the interests of science and society;

g) the necessary safeguards have been taken to protect the adult's privacy and to respect his/her dignity.

29. The above considerations closely mirror the preoccupations expressed in the amendments of the Committee on the Environment, Public Health and Consumer Policy of the European Parliament.

30. Nevertheless, some member organisations of Alzheimer Europe expressed their unease about the concept of "direct benefit" with regard to the conduct of clinical trials. Since most clinical trials include people receiving a placebo, these organisations feared that these trials could be questioned since no lasting "direct benefit" can be expected for the people receiving placebo. This issue deserves further clarification, as the position of Alzheimer Europe regarding "direct benefit" for research participants should in no way be construed as being opposed to the safe conduct of clinical trials.

31. Some scientists also say that the obligation of "direct benefit" would put into question the inclusion of people with dementia in Phase I drug trials where the safety of a medicinal product should be analysed. According to our information, Phase I trials do not, as a rule, involve people with the condition for which the product has been developed, but rather healthy individuals, since the aim of the study is not to show the efficacy, but only the safety of a given product.

32. On the question of whether people with dementia should be able to participate in clinical trials without potential direct benefit for them and without them having explicitly consented to the research, no consensus position could be reached between the member organisations of Alzheimer Europe. Most organisations reserved their judgement on this issue, unaware of the kind of clinical trials that may be covered by this definition.

33. We would therefore be grateful to be informed by the scientific community and the pharmaceutical industry about which clinical trials might be jeopardised by the current position of Alzheimer Europe limiting its approval to clinical trials with a "direct benefit" for participants.

34. Alzheimer Europe and its member organisation would welcome the organisation of a true dialogue on this subject between the interested parties; i.e. political decision makers, patients' and carers' organisations, the pharmaceutical industry and researchers in the field.

Other considerations

35. Consent to clinical trials, whether by the person with dementia or his/her legal representative should always be given in writing.

36. At any time during the clinical trial, the person with dementia or his/her legal representative shall be able to withdraw their consent. Also, any non-verbal indications by the person of his/her unwillingness or discomfort to continue the clinical trial, shall be justifiable reasons to discontinue the research.

37. Alzheimer Europe strongly supports the amendment of the Committee on the Environment, Public Health and Consumer Policy to ensure that patients or patients' representatives are included in or, at the very least, fully consulted by ethics committees in charge of endorsing the research protocol.

38. In case of conflict of interest, when the treating doctor and the doctor in charge of the clinical trial are identical, a second opinion by a doctor not implicated in the research will be necessary.

Annex 1 - The European Convention on Human Rights and Biomedicine

39. Article 16 of the European Convention on Human Rights and Biomedicine clearly sets out when research can be carried out on human beings.

Article 16 – Protection of persons undergoing research

Research on a person may only be undertaken if all the following conditions are met:

i. there is no alternative of comparable effectiveness to research on humans;

ii. the risks which may be incurred by that person are not disproportionate to the potential benefits of the research:

iii. the research project has been improved by the competent body after independent examination of its scientific merit, including assessment of the importance of the aim of the research, and multidisciplinary review of its ethical acceptability;

iv. the persons undergoing research have been informed of their rights and the safeguards prescribed by law for their protection;

v. the necessary consent as provided for under Article 5 has been given expressly, specifically and is documented. Such consent may be freely withdrawn at any time.

40. Article 17 of the Convention stipulates further conditions for the participation of persons not able to consent to research:

Article 17 – Protection of persons not able to consent to research

1. Research on a person without the capacity to consent as stipulated in Article 5 may be undertaken only if all the following conditions are met:

i. the conditions laid down in Article 16, sub-paragraphs i to iv, are fulfilled;

ii. the result sof the research have the potential to produce real and direct benefit to his or her health;

iii. research of comparable effectiveness cannot be carried out on individuals capable of giving consent;

iv. the necessary authorisation provided for under Article 6[5] has been given specifically and in writing; and

v. the person concerned does not object.

2. Exceptionally and under the protective conditions prescribed by law, where the research has not the potential to produce results of direct benefit to the health of the person concerned, such research may be authorised subject to the conditions laid down in paragraph 1, sub-paragraphs i, iii, iv and v above, and to the following additional conditions:

i. the research has the aim of contributing, through significant improvement in the scientific understanding of the individual's condition, disease or disorder, to the ultimate attainment of results capable of conferring benefit to the person concerned or other persons in the same age category or afflicted with the same disease or disorder or having the same condition;

ii. the research entails only minimal risk and minimal burden for the individual concerned.

Annex 2 - The Clinical Trials Directive

41. The Clinical Trials Directive underwent its second reading in the European Parliament and the Committee on the Environment, Public Health and Consumer Policy proposed significant amendments to the common position adopted by Council.[6]

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[5] Article 6 provides that if an adult does not have the capacity to consent, an intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.

[6] Recommendation for second reading A5-0349/2000, Committee on the Environment, Public Health and Consumer Policy, Rapporteur: Peter Liese

42. In particular, the following amendments were directly relevant for the participation of people with dementia in research.

Amendment 1

Persons who are incapable of giving legal consent to clinical trials must be given special protection. It is incumbent on the Member States to lay down rules to this effect. Such persons may not be included in clinical studies if the same results can be obtained using persons capable of giving consent.

Normally these persons should only be included in clinical trials where there are grounds for expecting that the administering of the medicinal product would be of direct benefit to the patient, which outweighs the risks.

Amendment 2

In the case of other person incapable of giving their consent, such as persons with dementia, psychiatric patients etc., inclusion in clinical trials in such cases should be on an even more restrictive basis.

Medicinal products for trial may be administered to individuals without exception when there are grounds for assuming that the direct benefit to the patient outweighs the risks.

Moreover, in such cases the written agreement of the patient's legal representative, given in cooperation with the treating doctor, is necessary before participation in any such clinical trial.

Amendment 13

In the case of other persons incapable of giving informed legal consent, all requirements listed for persons capable of giving consent and for children shall apply. In addition to these requirements, inclusion in clinical trials of incapacitated adults who have not given or not refused informed consent prior to the onset of their incapacity shall be allowed only if:

1. *Such research is essential to validate data obtained in clinical trials on persons able to give informed consent or by other research methods and which relates directly to a life-threatening or debilitating clinical condition from which the incapacitated adult concerned suffers;*
2. *The protocol has been endorsed by an Ethics Committee with expertise in the relevant disease and the patient population concerned or after taking advice in clinical, ethical and psycho-social questions in the field of the relevant disease and the patient population concerned.*
3. *There are grounds for expecting that administering the medicinal product to be tested will produce a benefit to the patient outweighing the risks.*

8 Annex II: Position paper on genetic testing

Executive Summary

1. The present paper constitutes the input of Alzheimer Europe and its member organisations to the ongoing discussions within Europe about genetic testing (in the context of Alzheimer's disease and other forms of dementia).

2. Alzheimer Europe would like to recall some general principles which guide this present response:

   a) Having a gene associated with Alzheimer's disease or another form of dementia does not mean that a person has the disease.

   b) People who have a gene linked to Alzheimer's disease or another form of dementia have the same rights as anyone else.

   c) Genetic testing does not only affect the person taking the test. It may also reveal information about other relatives who might not want to know.

   d) No genetic test is 100% accurate.

   e) The extent to which health cover is provided to citizens by the State social security system and/or privately contracted by individuals differs from one country to the next.

3. On the basis of these principles, Alzheimer Europe has developed the following position with regard to genetic testing:

   a) Alzheimer Europe firmly believes that the use and/or possession of genetic information by insurance companies should be prohibited.

   b) Alzheimer Europe strongly supports research into the genetic factors linked to dementia which might further our understanding of the cause and development of the disease and possibly contribute to future treatment.

   c) Based on its current information, Alzheimer Europe does not encourage the use of any genetic test for dementia UNLESS such test has a high and proven success rate either in assessing the risk of developing the disease (or not as the case may be) or in detecting the existence of it in a particular individual.

   d) Alzheimer Europe requests further information on the accuracy, reliability and predictive value of any genetic tests for dementia.

   e) Genetic testing should always be accompanied by adequate pre- and post-test counselling.

   f) Anonymous testing should be possible so that individuals can ensure that such information does not remain in their medical files against their will.

Introduction

4. It is extremely important for people with dementia to be diagnosed as soon as possible. In the case of Alzheimer's disease, an early diagnosis may enable the person concerned to benefit from medication, which treats the global symptoms of the disease and is most effective in the early to mid stages of the disease. Most forms of dementia involve the gradual deterioration of mental faculties (e.g. memory, language and thinking etc.) but in the early stages, it is still possible for the person affected to make decisions concerning his/her finances and care etc. – hence the importance of an early diagnosis.

5. If it were possible to detect dementia before the first symptoms became obvious, this would give people a greater opportunity to make informed decisions about their future lives. This is one of the potential benefits of genetic testing.

6. On the other hand, such information could clearly be used in ways which would be contrary to their personal interests, perhaps resulting in employment discrimination, loss of opportunities, stigmatisation, increased health insurance costs or even loss of health insurance to name but a few examples.

7. The present discussion paper outlines some of the recommendations of Alzheimer Europe and its member organisations and raises a few points which deserve further clarification and discussion.

The necessity for a response by Alzheimer Europe

8. In the last few years, the issue of genetic testing has been increasingly debated. In certain European countries there are already companies offering such tests. Unfortunately, the general public do not always fully understand what the results of such tests imply and there are no regulations governing how they are carried out i.e. what kind of information people receive, how the results are presented, whether there is any kind of counselling afterwards and the issue of confidentiality etc.

9. In order to provide information to people with dementia and other people interesting in knowing about their own state of health and in order to protect them from the unscrupulous use of the results of genetic tests, Alzheimer Europe has developed the present Position Paper.

General principles

10. At its Annual General Meeting in Munich on 15 October 2000, Alzheimer Europe adopted recommendations on how to improve the legal rights and protection of adults with incapacity due to dementia. This included a section on bioethical issues. These recommendations obviously need to guide any response of the organisation regarding genetic testing for people who suspect or fear they may have dementia and also those who have taken the test and did develop dementia.

    a) The adult with incapacity has the right to be informed about his/her state of health.

    b) Information should, where appropriate, cover the following: the diagnosis, the person's general state of health, treatment possibilities, potential risks and consequences of having or not having a particular treatment, side-effects, prognosis and alternative treatments.

    c) Such information should not be withheld solely on the grounds that the adult is suffering from dementia and/or has communication difficulties. Attempts should be made to provide information in such a way as to maximise his/her ability to understand, making use of technology and other available techniques to enhance communication. Attention should be paid to any possible difficulty understanding, retaining information and communicating, as well as his/her level of education, reasoning capacity and cultural background. Care should be taken to avoid causing unnecessary anxiety and suffering.

    d) Written as well as verbal information should always be provided as a back-up. The adult should be granted access to his/her medical file(s). S/he should also have the opportunity to discuss the contents of the medical file(s) with a person of his/her choice (e.g. a doctor) and/or to appoint someone to receive information on his/her behalf.

    e) Information should not be given against the will of the adult with incapacity.

f) The confidentiality of information should extend beyond the lifetime of the adult with incapacity. If any information is used for research or statistical purposes, the identity of the adult with incapacity should remain anonymous and the information should not be traceable back to him/her (in accordance with the provisions of national laws on respect for the confidentiality of personal information). Consideration should be given to access to information where abuse is suspected.

g) A clear refusal by the adult with incapacity to grant access to information to any third party should be respected regardless of the extent of his/her incapacity, unless this would be clearly against his/her best interests e.g. carers should have provided to them information on a need to know basis to enable them to care effectively for the adult with incapacity.

h) People who receive information about an adult with incapacity in connection with their work (either voluntary or paid) should be obliged to treat such information with confidentiality.

Genetic testing

11. These general principles as well as the Convention of Human Rights and Biomedicine (see Annex 1) and the Universal Declaration on the Human Genome and Human Rights (see Annex 2) dictate Alzheimer Europe's position with regard to genetic testing.

12. Alzheimer Europe would like to draw a distinction between tests which detect existing Alzheimer's disease and tests which assess the risk of developing dementia Alzheimer's disease at some time in the future:

a) Diagnostic testing: Familial early onset Alzheimer's disease (FAD) is associated with 3 genes. These are the amyloid precursor protein (APP), presenilin-1 and presenilin-2. These genetic mutations can be detected by genetic testing. However, it is important to note that the test only relates to those people with FAD (i.e. about 1% of all people with Alzheimer's disease). In the extremely limited number of families with this dominant genetic disorder, family members inherit from one of their parents the part of the DNA (the genetic make-up), which causes the disease. On average, half the children of an affected parent will develop the disease. For those who do, the age of onset tends to be relatively low, usually between 35 and 60.

b) Assessment for risk testing: Whether or not members of one's family have Alzheimer's disease, everyone risks developing the disease at some time. However, it is now known that there is a gene, which can affect this risk. This gene is found on chromosome 19 and it is responsible for the production of a protein called apolipoprotein E (ApoE). There are three main types of this protein, one of which (ApoE4), although uncommon, makes it more likely that Alzheimer's disease will occur. However, it does not cause the disease, but merely increases the likelihood. For example, a person of 50, would have a 2 in 1,000 chance of developing Alzheimer's disease instead of the usual 1 in 1,000, but might never actually develop it. Only 50% of people with Alzheimer's disease have ApoE4 and not everyone with ApoE4 suffers from it.

There is no way to accurately predict whether a particular person will develop the disease. It is possible to test for the ApoE4 gene mentioned above, but strictly speaking such a test does not predict whether a particular person will develop Alzheimer's disease or not. It merely indicates that he or she is at greater risk. There are in fact people who have had the ApoE4 gene, lived well into old age and never developed Alzheimer's disease, just as there are people who did not have ApoE4, who did develop the disease. Therefore taking such a test carries the risk of unduly alarming or comforting somebody.

13. Alzheimer Europe agrees with diagnostic genetic testing provided that pre- and post-test counselling is provided, including a full discussion of the implications of the test and that the results remain confidential.

14. We do not actually encourage the use of genetic testing for assessing the risk of developing Alzheimer's disease. We feel that it is somewhat unethical as it does not entail any health benefit and the results cannot actually predict whether a person will develop dementia (irrespective of the particular form of ApoE s/he may have).

15. We are totally opposed to insurance companies having access to results from genetic tests for the following reasons:

    a) This would be in clear opposition to the fundamental principle of insurance which is the mutualisation of risk through large numbers (a kind of solidarity whereby the vast majority who have relatively good health share the cost with those who are less fortunate).

    b) Failure to respect this principle would create an uninsurable underclass and lead to a genetically inferior group.

    c) This in turn could entail the further stigmatisation of people with dementia and their carers.

    d) In some countries, insurance companies manage to reach decisions on risk and coverage without access to genetic data.

16. We therefore urge governments and the relevant European bodies to take the necessary action to prohibit the use or possession of genetic data by insurance companies.

17. Alzheimer Europe recognises the importance of research into the genetic determinants of Alzheimer's disease and other forms of dementia. Consequently,

    a) we support the use of genetic testing for the purposes of research provided that the person concerned has given informed consent and that the data is treated with utmost confidentiality; and

    b) we would also welcome further discussion about the problem of data management.

18. In our opinion, any individual who wishes to take a genetic test should be able to choose to do so anonymously in order to ensure that such information does not remain in his/her medical file.

Other considerations

19. People who take genetic tests and do not receive adequate pre and post test counselling may suffer adverse effects.

20. Fear of discrimination based on genetic information may deter people from taking genetic tests which could be useful for research into the role of genes in the development of dementia.

21. Certain tests may be relevant for more than one medical condition. For example, the ApoE test is used in certain countries as part of the diagnosis and treatment of heart disease. There is therefore a risk that a person might consent for one type of medical test and have the results used for a different reason.

Annex 1: The Convention on Human Rights and Biomedicine (Council of Europe - Oviedo, 1997)

22. The following extracts from the above mentioned convention should be borne in mind:

- ?? Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.

- ?? Everyone has the right to respect for private life in relation to information about his or her health.

- ?? Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.

- ?? Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.

Annex 2: Universal Declaration on the Human Genome and Human Rights (UNESCO, 1997)

23. The following extracts from the above mentioned declaration should be borne in mind:

- ?? Everyone has a right to respect for their dignity and for their human rights regardless of their genetic characteristics.

- ?? That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity.

- ?? The right of each individual to decide whether to be informed or not of the results of genetic examination and the resulting consequences should be respected.

- ?? No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.

- ?? Genetic data associated with an identifiable person and stored or processed for the purposes of research or any other purpose must be held confidential in the conditions foreseen by law.

9 Annex III: The member organisations of Alzheimer Europe

9.1 Full member organisations

Austria

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Greek Association of Alzheimer's Disease and Related Disorders (GAADRD)
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Ireland

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www.solitel.es/alzheimer/alzheimer.htm

Sweden

Alzheimerföreningen i Sverige
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www.alzheimerforeningen.nu

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for Scotland

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9.2 Associate member organisations

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10 Annex IV: Alzheimer Europe Publications

Annual report

The **Annual Reports** of the organisation can be ordered free of charge from Alzheimer Europe:

- Annual report 2001
- Annual report 2000
- Annual report 1999
- Annual report 1998
- Annual report 1997/96

Care manual

The **Care Manuals** are destined for family members and people taking care of a person with Alzheimer's disease or a related dementia. The manual provides general information on dementia and Alzheimer's disease, as well as more specific information about symptoms and how to cope.

Currently, the following language editions are available: Danish, French, German, Greek, Italian, Portuguese, Turkish.

All these Care Manuals can be ordered from Alzheimer Europe or from the concerned member organisations. They are sold for €10, but please allow for €2.5 postage costs, if you are living in Europe and €5.5 postage costs if you are living outside Europe.

Children book

The Children's book relates a story of the daily life of a family in which the grandmother is suffering from Alzheimer's disease. The story is portrayed through the eyes of one of the grandchildren. It is targeted at children from 9 to 11 years of age.

Currently, the following language editions are available: Danish, Dutch, French, German, Greek and Italian.

All these books can be ordered from Alzheimer Europe or from the concerned member organisations. They are sold for €5, but please allow for €2.5 postage costs, if you are living in Europe and €5.5 postage costs if you are living outside Europe.

Conference proceedings

1st Alzheimer Europe Forum Proceedings.

"The future of Alzheimer's disease and dementia in Europe: Hopes and fears about the development of anti-dementia drugs", Brussels, BELGIUM - 1999, 54 pages

2nd Alzheimer Europe Forum Proceedings.

"The legal rights of people with dementia", Luxembourg, LUXEMBOURG – 2000, 80 pages

3rd Alzheimer Europe Forum Proceedings

"Equality of access to care and treatment", Brussels, BELGIUM – 2001, 50 pages

These proceedings can be obtained from Alzheimer Europe for 5€ per copy. Please allow for for €2.5 postage costs, if you are living in Europe and €5.5 postage costs if you are living outside Europe.

Position papers

Position paper 1

Recommendations on how to improve the legal rights and protection of adults with incapacity due to dementia - 2001, 12 pages

Position paper 2

Guidelines on the use of various measures designed to restrict liberty of movement - 2001, 8 pages

Position paper 3

Advance directive (living will) - 2001, 8 pages

These threes position papers are available in the following languages: Danish, Dutch, English, Finnish, French, German, Greek, Portuguese, Spanish and Swedish.

They can be obtained from Alzheimer Europe for 1.5€ per copy. Please allow for for €1 postage costs, if you are living in Europe and €1.5 postage costs if you are living outside Europe. If you are ordering multiple copies, please contact the Alzheimer Europe secretariat for the postage costs.

11 Alzheimer Europe

11.1 Board Members

Chairperson:

Jeannot Krecké, Association Luxembourg Alzheimer (Luxembourg)

Vice-Chairperson:

Jacques Selmes, Fundación Alzheimer España (Spain)

Honorary Secretary:

Antonia Croy, Alzheimer Angehörige Austria (Austria)

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