



***Look to the
Future
2011 – 2015***



***Strategy of the
Diabetes Federation of Ireland***

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Foreword

In the past number of years, the Diabetes Federation of Ireland has developed into a strong national organisation that supports the diabetes community in Ireland. It has strived to develop services that meet the needs of its community, raise diabetes awareness among the wider community and advocate for improvements in diabetes health service provision. It has also substantially increased its funding of high quality diabetes research projects in Ireland.

With the Institute of Public Health anticipating a 62% increase in the prevalence of diabetes by 2020 to over 232,000 people in Ireland, access to Federation services will become even more important for people with diabetes.

This strategy continues and builds on past work specifically in the areas of education, advocacy, health promotion and research and sets out targets which if achieved will no doubt enhance the lives of people with diabetes nationwide.

To achieve this, the Diabetes Federation of Ireland will continue to require the support of the diabetes community and over the next five years, I sincerely hope the Federation continues to receive the support it needs to deliver on the targets set out in this strategy document.

James Byrne
Chairperson

Section 1

Diabetes Federation of Ireland

Since 1967, the Diabetes Federation of Ireland is the national charity dedicated to helping people with diabetes. It achieves this by providing support, education and motivation to all people affected by diabetes. The Federation also raises public awareness of diabetes and its symptoms and funds Irish based research into finding a cure for diabetes.

Through its network of local support branches throughout the country, people who have an interest in diabetes are dedicated to sourcing and sharing information on diabetes and related matters.

1.1 Mission and Aims

Mission

To provide a quality service in improving the lives of people affected by diabetes, and working with others to prevent and cure diabetes.

Aims

- (i) To provide support, information and motivation for people with diabetes, their families and friends
- (ii) To raise awareness of diabetes in the community and foster programs for early detection and prevention of diabetes
- (iii) To support and encourage advances in diabetes care and research.

Activities of the organisation

The Diabetes Federation of Ireland provides a range of services which include:

- Patient Support via its telephone lo-call helpline and local support branches
- Information via leaflets, information packs, website, Diabetes Ireland magazine.
- Support for children and parents with diabetes via the Sweetpea Kidz Club; children and adolescent activity days, family education weekends, parent support groups
- Direct health education for patients (CODE); patient conferences, Adolescent conferences
- Financial services; negotiated motor and health insurance rates
- Advocacy and liaison; with clinics, services, HSE and the DOHC
- Anti-discrimination activity; Insurance industry, Employers

- Professional support; Professional Services Section, major annual multi-disciplinary conference, practice support packs and Diabetes Professional magazine
- Public awareness; T4DI initiative , Poster awareness campaigns,
- Health Promotion initiative including schools awareness, workplace awareness, early detection and prevention initiatives, diabetes screening
- Funds research in Ireland

1.2 Key Services

The Diabetes Federation of Ireland provides a range of services for people with diabetes and the general public. Services include:

Patient Support

Being diagnosed with diabetes can be very traumatic. Therefore, it can be difficult to be receptive to all the new information about diabetes. One of the main support mechanisms for people with diabetes is immediate access to up to date quality information. The Federation provides support and information to individuals. Access to services is via the following:

➤ **Telephone lo-call helpline**

The Lo-call Diabetes helpline is open from 9am-5pm Monday – Friday and can be accessed from anywhere in Ireland and for any duration for €0.25 cent. It provides information on a range of issues ranging from general information on diabetes, complications of diabetes, discrimination in the workplace/school and by the insurance industry, symptoms of diabetes, peer support in relation to a diagnosis of diabetes and coming to terms with the lifestyle change on both the individual and their family.

The total number of callers has increased annually from 2,500 in 2002 annually to over 6,600 callers in 2009 reflecting increased awareness and use of the service by the diabetes community.

The increase in the annual number of callers to the helpline year on year highlights the continuing need for this service. Seventy-seven per cent of callers in 2009 were seeking general information about the management of diabetes. The majority of those callers were sent educational literature as part of this service. We are also seeing the service used increasingly by allied health professionals such as GPs and pharmacists particularly in the area of patient education.

The helpline team are kept abreast of breaking news issues by healthcare professional staff and are advised on appropriate responses to the general public.

➤ **Website**

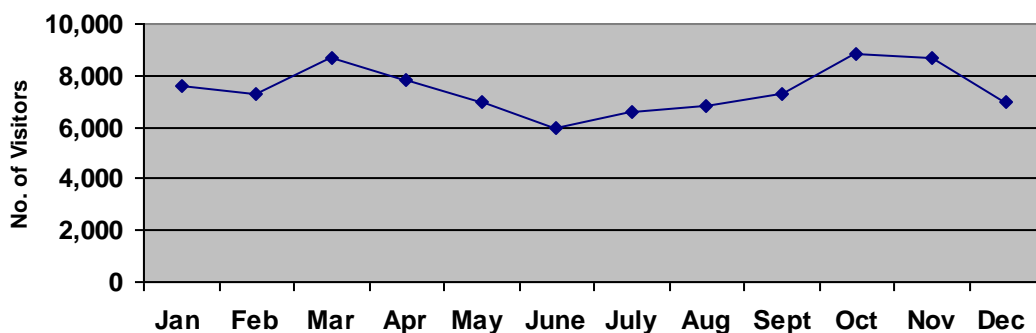
The Federation has an excellent website resource at www.diabetes.ie for people seeking quality information on all aspects of diabetes. Visitors to the site is increasing steadily from 62,500 users spending on average 8 minutes in the site in 2003 to 84,501 users spending on average 8.25 minutes in the site in 2009 reflecting the increasing use of the web as an information source.

The website has an online payment facility and shop where users can become a member and access Diabetes Federation of Ireland approved products. To aid people who require background information about diabetes, diabetes services and management in Ireland, a section of www.diabetes.ie is also devoted to published downloadable reports. With this facility, it is now possible to download a variety of national publications related to diabetes from a central point.

With electronic support becoming more common, the Diabetes Federation of Ireland must respond by updating their website www.diabetes.ie with more user friendly links and using other technology pathways to disseminate quality information.

Monthly increases in visitor numbers was notable at times of the year that the Federation had increased national coverage on radio and through public events (see graph 1)

Visitors to Diabetes Website 2009



In 2009, 84,501 people visited the website spending on average 8.25 minutes.

➤ **Local support branches & offices**

The Federation has a Head Office and 2 regional offices plus 23 local support groups. The local support groups, run on a voluntary basis, provide local support to the diabetes community via public education forums and diabetes awareness campaigns. Regional offices provide the full range of Federation services in their locality.

The Sweetpea Kidz Club is specifically for children with diabetes and their siblings with no strict age limit. The aims of the Club are to provide an opportunity for children with diabetes and their families to meet in a fun environment, provide information and support for families with diabetes.

With so many negative aspects to the condition, the Club offers some light relief for all involved and it is hoped that providing a club at such a young age may encourage children to continue their involvement in the Federation at youth level.

Activities are aimed at children up to the age of twelve years but children are welcome to remain on as members of the club until they feel that they have outgrown the Club's activities. The activities organised by the Club range from parties to day-trips and family education weekends.

The Federation also hold an annual adolescent adventure trips with the aim of encouraging participants to engage in adventure activities in a fun environment and make new friends.

➤ ***Information***

People with diabetes require access to information that is easily accessible and appropriate to their needs. The Federation provides written information on all aspects of diabetes. The Federation acknowledge that literature is time specific and due to the evolving nature of diabetes management and changing technologies, all literature needs to be updated regularly and new written information leaflets/booklets need to be developed as funding permits.

The Federation has an extensive range of information leaflets about diabetes and related areas. In order to facilitate people and professional healthcare workers accessing these publications in a timely fashion, pdf copies of a range of them are available on www.diabetes.ie.

Its quarterly magazines "Diabetes Ireland" and "Diabetes Professional" keeps people up to date on latest developments, in diabetes, healthy eating, exercise, events local and national and many other issues. Diabetes Ireland is distributed to all members while Diabetes Professional is distributed to all healthcare professional members plus a range of allied healthcare professionals interested in diabetes. Diabetes Ireland has 8,000 readers and Diabetes Professional 5,000 readers per issue respectively.

Patient Education

Community Orientated Diabetes Education Programme

Many people with diabetes in Ireland have limited access to community diabetes education services. In 2007, the Diabetes Federation of Ireland launched its patient education programme, Community Orientated Diabetes Education (CODE) for people with Type 2 diabetes. Part funded by the HSE, the programme is based on the philosophy that it is people with diabetes who make the decisions concerning their own care on a daily basis. Empowerment acknowledges that individuals have different capabilities and their diabetes goals must reflect that capacity.

CODE is a programme which delivers general information about diabetes and acknowledges that diabetes education must be a continuous and methodical process. CODE supports and supplements care from the individual's own diabetes team so that knowledge and skills are reinforced and the taking of responsibility for personal self-management of diabetes is gradually strengthened.

CODE is a dynamic process with sufficient flexibility to permit people with diabetes to talk in a supportive atmosphere about their own diabetes for the benefit of all in the group. It is up to the person themselves to evaluate the benefits and drawbacks of any action or inaction. It is through this personal evaluation that inner motivation is reinforced by the perception of having a choice. The aim is to achieve behavioural change through a mutually agreed course of action. It is accepted that behavioural change will vary among individuals and that goals must reflect the variability of individual capacity and desires.

The CODE programme for people with Type 2 diabetes (CODET2) targets people with diabetes who receive their care at primary care level and who have limited access to diabetes specialist professionals. The programme is delivered over three successive weeks with a telephone support session at 10 weeks and a follow-up support/appraisal session at 26 weeks.

From 2007 to 2009, 101 CODET2 programmes were delivered throughout Ireland with a total of 1343 people attending.

CODE T1

In 2008, as a result of requests from parents to meet and talk to other parents outside the healthcare environment, the Diabetes Federation of Ireland developed a CODE T1 workshop to meet the needs of parents of children with diabetes.

Parents report inordinate amounts of stress coping with the complex diabetes regime of insulin, diet and exercise and intrusive nature of diabetes management. Diabetes intrudes emotionally and practically upon all aspects of their lives. Parents report seeking more information on dietary food choices so that their child with diabetes can have a consistent carbohydrate intake but still

have similar choices to his/her peers. A diagnosis of diabetes leads to losses for parents, who experience a grief reaction similar to that commonly associated with bereavement. Recent research on children with type 1 diabetes and their families suggest that sustaining parental involvement and minimizing parent –child conflict are essential for improved health outcomes.

CODE T1 is a supportive interactive workshop for parents who have children with type 1 diabetes. It involves two 2 hour sessions, one with a Dietitian/Nurse and a session with a Counsellor/Nurse.

Since 2008, xx programmes were delivered nationwide with a total of xx participants attending. Ongoing peer support is required for parents.

Diabetes Detection, Promotion and Prevention

➤ **Public awareness**

The Diabetes Federation of Ireland has been at the forefront of raising awareness of diabetes in Ireland in the past 5 years. It organises annual public awareness campaigns on the symptoms and prevention of diabetes, the benefits of healthy eating, exercise and living a healthier lifestyle. National and local campaigns are run throughout the year.

➤ **Diabetes Promotion**

The Diabetes Federation has a detailed Health Promotion initiative in place that includes raising awareness of diabetes and its symptoms in schools, workplace and community care settings. Early detection and prevention initiatives such as diabetes screening days are also held throughout the country.

The initiative also provides educational support to healthcare professionals working in the diabetes area. Through its Professional Services Section a major multi-disciplinary conference is held annually along with regional professional meetings.

➤ **Diabetes Counselling**

The Diabetes Federation of Ireland has set up a diabetes educational module for accredited counsellors. The psychosocial impact of diabetes can create a heavy burden on individuals and families. It is acknowledged that the medical team attempt to address these issues. However, the makeup of medical teams in Ireland aside from those with specialist psychosocial support, have had little or no formal training in counselling, stress management or behaviour modification. The course was designed to help counsellors gain an understanding of day-to-day living with diabetes.

A qualified list of counsellors who can offer a private service to a person with diabetes is available on www.diabetes.ie .

➤ **Anti-discrimination activity**

The Diabetes Federation of Ireland actively lobbies on behalf of people with diabetes in areas where they have been discriminated. It has been successful in getting medication for high cholesterol and high blood pressure on to the Long Term Illness booklet for patients.

It is also actively advocating against discrimination in the workplace and in schools and seeking the removal of employment blanket bans in those professions that have them.

➤ **Financial Services**

Insurance cover is a major issue for people with diabetes and the Diabetes Federation of Ireland advocates for its members equal access to insurance cover similar to those people who do not have diabetes. The Federation has in place a range of preferential insurance schemes for members. These are:

- (i) a Specified Illness/Group Life scheme which allows people with diabetes aged between 18 and 60 years and parents of children with diabetes under 18 to obtain cover without providing any medical information and without the burden of extra premiums due to their condition.
- (ii) a motor insurance scheme for members with preferential premiums with no loadings for people with diabetes and a 5% discount on normal standard ratings.
- (iii) an annual multi-trip insurance travel policy that is not modified because of the presence of diabetes
- (iv) mortgage and mortgage protection cover offering competitive rates to members.

➤ **Advocacy**

The Diabetes Federation of Ireland actively seeks to develop partnerships with all parties involved in providing a quality service for people with diabetes. These include links with acute sector diabetes clinics, primary health care providers, the Department of Health and Children and its health boards, other voluntary and healthcare professional organisations and the International Diabetes Federation.

Following the publication of the HSE's Diabetes Expert Advisory Group report, the Diabetes Federation needs to advocate for implementation of the report's recommendations.

➤ **Research**

The Diabetes Federation of Ireland supports research to improve treatments and to find a cure or prevention for diabetes. Through its subsidiary charity, Diabetes Ireland Research Alliance, it will continue to promote Ireland as a

suitable base for diabetes research and continue to fund high quality research projects.

Section 2

Future Challenges

In terms of future challenges, the Diabetes Federation of Ireland has identified 4 key areas to focus on namely education, advocacy, health promotion and research. The objectives and targets for each of these key areas are:

2.1 Education

Objective

To encourage, facilitate and improve patient education and support for the diabetes community.

Goals

1. Provide easy access to Diabetes Federation of Ireland patient support services.
2. Provide easy to read, up-to-date quality information on diabetes for people with diabetes, their families and healthcare professionals.
3. Strengthen and improve patient self-management of their condition by enhancing their knowledge of diabetes.

Why is this important to us

The global incidence of diabetes is increasing rapidly. Ireland is not exception to this and it is anticipated that the prevalence of diabetes in Ireland will increase by 62% to 232,000 by 2020.

Irish diabetes healthcare services are not expanding in line with increasing diabetes patient numbers. Many diabetes patients are not getting access to appropriate information and support at their time of need. The Diabetes Federation of Ireland supports the efforts of hard working, under-resourced diabetes healthcare professionals through the provision of easily accessible education, support and information systems and access to structured education programmes to people with diabetes so they can effectively manage their condition.

Key education and support services/initiatives:

Lo-call Diabetes Helpline
Diabetes Information Website
Diabetes Literature
CODE Type 2 Structured Education programme
Local Branch Volunteer Network
Parents Support Network

2011 -2015 Tasks

- (a) Improve public promotion of both the Lo-call Diabetes Helpline and website services nationally.
- (b) Develop a more up-to-date and user friendly website. Use other forms of appropriate on-line technology to promote activities and initiatives
- © Review and update information literature and make it more widely available in the community.
- (d) Develop a Diabetes Federation Type 1, Type 2 and Paediatric Information pack for new members.
- (e) Expand the number of CODE T2 programmes delivered nationwide.
- (f) With stakeholders, investigate the viability of becoming a national administrative structured education support & training centre
- (g) Expand the number of CODE T1 for parents nationwide.
- (h) Investigate the viability of supporting an existing education programme for children & adolescents in Ireland.
- (i) Develop and support a National Parent's Support Section to meet the needs of this section.

2.2 Advocacy

Objective

Influence policy relating to diabetes issues specifically the need for improved national diabetes healthcare services and removal of inequality issues.

Goals

1. Seek to remove inequality issues that can affect career and lifestyle choices of people with diabetes.
2. Engage the diabetes community to advocate for implementation of the Health Service Executive's (HSE) Diabetes Expert Advisory Group Report's recommendations.
3. Put diabetes health on the agenda of all policy makers at all levels of government, directing them to be more aware of the health consequences of their decisions and to accept that all actions have an impact on the general health of the nation.

Why is this important to us

Due to age old legislation, people with diabetes can be prevented from undertaking certain career options. Existing employment blanket bans, while necessary many years ago in some areas, are now out of date as new medications and technologies significantly improve management and thus negate the reasons for putting the legislation in place. Today, people with diabetes should have the opportunity to apply for entry into their chosen careers under a scheme of individual assessment.

Research has shown that intense management of diabetes can prevent and reduce the onset of complications and improve quality of care. The implementation of the HSE's Diabetes Expert Advisory Group report will significantly reduce the personal and economic burden of diabetes in Ireland. The Diabetes Federation of Ireland must continue to engage with all stakeholders for improved health service delivery.

2011 -2015 Tasks

- (a) In conjunction with mutual stakeholders, the Diabetes Federation of Ireland will actively promote/advocate for implementation of the recommendations of the HSE's Diabetes Expert Advisory Group at national and local level.
- (b) The Federation will support the work of the tri-partite Diabetes Advocacy Group that represents the medical profession, patients and industry and aims to advocate for a National Diabetes Strategy and raise awareness of diabetes symptoms & risk factors among the general population.
- © The Federation will work with the HSE, Department of Health and Children, diabetes healthcare professional organisations, corporate partners and other interested stakeholders involved in providing a quality service to all members of the diabetes community regardless of age and location.
- (d) Work to ensure that people with diabetes has information, and access, about all diabetes medications and technologies.
- (e) In conjunction with other Chronic Illness voluntary organisations, the Diabetes Federation of Ireland will produce a "Schools Policy Guidelines" document for dissemination to all primary and post primary schools in Ireland. The document will set out guidelines for managing the student with a chronic illness including diabetes during school hours.
- (f) To coincide with this document, the Diabetes Federation of Ireland will produce a supporting DVD for use by teachers.
- (g) The Diabetes Federation of Ireland will continue to actively support and educate teachers on coping with their student with diabetes.
- (h) The Diabetes Federation of Ireland will work to remove blanket bans and other barriers that prevent people with diabetes from undertaking their chosen careers and having easy access to all forms of insurance cover without

penalties. It will continue to do this by looking to educate, liaise and work with appropriate stakeholders in order to remove existing barriers.

2.3 Health Promotion

Objective

To enable people with diabetes and their families and people at risk of developing diabetes to improve their general health.

Goals

1. To educate and motivate people with diabetes to improve management of their condition.
2. Improve earlier detection and prevention of diabetes in the wider community, specifically targeting those at high risk of developing diabetes..
3. Increase awareness of diabetes and its symptoms among the wider community.

Why is this important to us

Early detection of diabetes is a major factor in preventing/reducing complications i.e. microvascular and macrovascular problems in later life. Public awareness initiatives and targeted screening programmes will improve early detection of diabetes and increase public awareness of diabetes.

The Federation aims to encourage earlier diagnosis and better understanding of diabetes thereby reducing the prevalence of diabetes related complications requiring hospitalisation. This will enhance the quality of life of people with diabetes and reduce the economic burden of diabetes.

2011 -2015 Tasks

- (a) The Diabetes Federation of Ireland will target neglected areas for diabetes detection, specifically families of people with diabetes, other high risk groups and community care settings with limited healthcare access.
- (b) The Federation will undertake public diabetes screening events in community settings such as local pharmacies and shopping centres, high profile local events and in the workplace.
- © The Federation will increase public awareness of diabetes, its symptoms and risk factors and the benefits of living a healthier lifestyle through national and local publicity campaigns.
- (d) Promote the benefit of exercise/healthy lifestyle initiatives in conjunction with the awareness of the risks of not following such a lifestyle.

2.4 Research

Objective

To advance the understanding of diabetes through research.

Goals

1. To conduct, promote, support and fund research related to the causes, prevention and cure of diabetes, and into improvements in the management of the condition and its complications
2. To publish and disseminate the useful results of diabetes research

Why is this important to us

The development of new and improved technologies will help people with diabetes to more effectively manage their condition thus enhancing their quality of life. Diabetes research will improve understanding of diabetes and offers the best hope of finding a cure. The Irish diabetes community wants to help achieve this by supporting and funding high quality global and Irish based diabetes research. The Diabetes Federation of Ireland facilitates through its subsidiary charity the Diabetes Ireland Research Alliance.

2011 -2015 Tasks

- (a) To encourage high quality Type 1 and Type 2 diabetes research in Ireland.
- (b) To promote Ireland as a base for international-led research into finding a cure for diabetes
- (c) To facilitate the opportunity for Irish donors to support international-led diabetes research.
- (d) To raise funds for diabetes research.

Conclusion

Services provided by the Diabetes Federation of Ireland significantly impact on the cost of care for people with diabetes in Ireland. With the huge anticipated increase in the prevalence of diabetes in Ireland, easy access to Federation support services is vital. Access to high quality patient education and improved diabetes health services will help the person with diabetes manage their condition more effectively.

Earlier diagnosis and better understanding of diabetes will reducing the current high level of diabetes related complications requiring hospitalisation.

Services provided by the Diabetes Federation of Ireland will continue to support, educate and motivate the diabetes community in Ireland.

Appendix 1

Diabetes Federation of Ireland Past Achievements

- Some of the numerous achievements of the Diabetes Federation of Ireland include:
- Continually helping, supporting, educating and motivating thousands of people with diabetes, their families and carers since 1967.
- Successfully lobbied for all diabetes medication and related high cholesterol and hypertensive medication to come under the Long Term Illness Scheme.
- Winner of the inaugural International Diabetes Federation “Diabetes Association of the Year Award” in 2000.
- Developing and producing a comprehensive range of literature including a bi-monthly magazine “Diabetes Ireland” and a quarterly magazine “Diabetes Professional”.
- Been the first diabetes support organisation to successfully bring a group of people with diabetes to the top of Kilimanjaro showing that there is no bar to people with diabetes from participating in arduous physical activity.
- Being the first organisation in Europe to have in place a Specified Illness & Whole of Life Insurance scheme specifically for people with diabetes.
- Successfully lobbying for the removal of blanket motor insurance premium loadings.
- Hosting, organising and facilitating International Health Conferences.
- Continually organising public and health professional education workshops and meetings for the diabetes community.
- Providing an ongoing national health promotion scheme to promote awareness and early detection of diabetes.
- Funding diabetes research in Ireland.
- Receiving an Irish Pharmaceutical Commendation Award for a project focussing on improving patient care in 2002.
- Winning the 2004 Irish Pharmaceutical Award for best public awareness initiative for its “Life Under 7” campaign, supported by sanofi-Aventis.

