

CARERS' NEWSLETTER (Western Isles)

SPRING 2003

ADVOCACY WESTERN ISLES

Advocacy involves an individual or group of individuals being supported to speak up for themselves or on behalf of others – to safeguard their interests and assert their right to be heard. Advocacy is needed because many people, especially those who experience difficulties arising from disabilities or ill health find it difficult to speak up for themselves or to get their views listened to. It is vital that people who use community services, including the most vulnerable and excluded in society, are able to make their voices heard and are genuinely involved in decisions that affect their lives.

Advocacy Western Isles is a new independent, confidential, free service which will be available throughout the Western Isles. The formal launch of the service by Mr David Currie, Chairman of the Western Isles NHS Board, took place in Stornoway on Wednesday 26th March after visits to Stornoway on Monday and to Benbecula on Tuesday by guests who were involved in training and awareness-raising sessions. Those visitors to the islands were Mr Tom Kohler - with 25 years experience in advocacy - from Chatham-Savannah Citizen Advocacy in Georgia, USA, Ms Adrienne Chalmers, Director and Ms Jo Mcfarlane, Development Worker both from the Advocacy Safeguards Agency, Edinburgh. Personnel from Voluntary and Statutory organisations attended the various sessions. In all, this involved 150 people over the three days.

The commitment shown over the past 18 months by Working Group and Management Committee members in developing this scheme from scratch has been considerable. Premises have now been rented in Bayhead, Stornoway from which the Co-ordinator operates. The post, at present, is part-time and the short-term aims will therefore have to be realistic with consequent prioritisation of the caseload. It is hoped that further funding can be accessed to allow the service to expand in response to anticipated demand. A number of volunteer advocates have already come forward and we would be interested to hear from anyone who would be prepared to devote some of their time to the furtherance of what is now regarded as an essential service. The intention is that the service should initially operate in specific areas of Health and Community Care and a progress report, including planned expansion of the service, will be contained in the next Newsletter.

John MacLean
Chairman, Advocacy Western Isles

Contact details: Advocacy Western Isles, 27 Bayhead, Stornoway. Tel/fax: 01851 701 755.

**If the office is not manned, contact the Community Care Forum on 01859 50 2588 or e-mail:
john.maclean2@virgin.net**

WESTERN ISLES COMMUNITY CARE FORUM
(JOINTLY FUNDED BY CNES AND THE WIHB)
WORKING TOGETHER IN COMMUNITY CARE
CO-ORDINATOR: JOHN MACLEAN

Old Hostel, Tarbert, Harris, HS3 3BG, Tel/Fax 01859 50 2588
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THE I REACH PROJECT

The **I Reach Project** started as a pilot scheme aimed at ensuring that adults with severe and enduring mental health problems living in the Western Isles could be provided with innovative types of enhanced social support to enable them to live independently in their own communities. The Project had two parts, raising awareness/information and a service model.

The lead role in the information aspect of the project was taken by the Western Isles Association for Mental Health and they have produced a Service Directory and are developing a website. This aspect of the **I Reach Project** has now been subsumed by the **Western Isles Patients and Carers Information Project**, an account of which follows.

The service model has evolved to become a fund that can be used creatively to meet the needs of individuals or groups, rather than a service. It has enabled many groups to develop or get started, for example a photography group, an Art Collective, a Depression Self-help Group, a creative writing group. Additionally, several individuals have benefited in a variety of ways, having identified what could help to enhance the quality of their lives.

The design of the project shows flexibility and this has proved to be its main strength. It has been used creatively to meet the needs of individual service users and referrers in ways that hitherto would not have been possible. It promotes and encourages social inclusion by providing people with the opportunity to meet with others and become involved in activities and events in their own communities and beyond. The fund also offers an opportunity for individuals to re-establish existing skills or to develop new ones. As it has demonstrated an approach to health and well-being that is person-centred and health promoting in the widest sense, the **I Reach Project** fits well with the current government agenda of promoting health and well-being, social inclusion and strengthening communities.

In its first year, the project was funded through the Mental Health Development Fund and has received recurrent funding from the Western Isles NHS Board for the last two years. This funding will continue.

The next step in the development of this project is a proposal that the management of the entire project becomes the responsibility of the Western Isles Association for Mental Health. The Mental Health Partnership has recently approved this proposal as a pilot scheme and arrangements will be in place shortly to facilitate this development.

For more information contact WIAMH, 23 Bayhead, Stornoway. Tel: 01851 704964.

Western Isles Patients & Carers **Information Project.**

This project is driven by the need to give accurate and appropriate information to NHS service users and their carers and to address the requirements of the Patient & Public Involvement initiatives. Funds had already been allocated to the Western Isles Association for Mental Health to attempt to meet these needs for people with mental health problems. However, it has been difficult to implement due to the constraints of time and people able and available to do this within the user group. An opportunity for additional funding arose through Volunteer Development Scotland/Primary Care Grants Fund and the proposal submitted was successful in attracting £35,000 of funding over the next two years.

This additional funding will enable the project to be extended beyond mental health to other national and local priority conditions. It will facilitate the employment of a Project Co-ordinator who will be able to take responsibility for setting up access points, training and supervising volunteers, liaising with GPs and other health professionals and establishing monitoring systems.

Providing accurate and appropriate information for people is an ongoing problem, particularly in an area such as the Western Isles with the inherent geographical and demographic difficulties. In the Stornoway area it is easier to ensure that printed information is available but this is not always enough in all cases and professional time is at a premium in remote and rural areas. Outwith the Stornoway area it is difficult to ensure that all printed information is available and regularly updated. It is envisaged that this project, using the technology available, will go a long way to addressing these problems.

As stated, the project will initially be aimed at priority groups and conditions and even this will have to be addressed incrementally. It is also hoped to include information on healthy lifestyles and other health promotion material.

A representative Project Management Group has been set up and it is hoped to appoint the Project Co-ordinator within the next few months.

Articles on Direct Payments and the Independent Living Fund will appear in the next issue of the Newsletter.

AGE CONCERN produce a range of factsheets on topics including residential care, benefits and paying for care. To order these factsheets contact Age Concern Scotland on 0131 467 7118 or call their information line on 0800 00 99 66.

**WESTERN ISLES KIDNEY PATIENTS’
ASSOCIATION**

Who are we?

The Western Isles Kidney Patients’ Association is available to provide assistance and information on all aspects of renal failure and related medical problems.

We hold regular monthly meetings on the last Thursday of the month at Grianan, Westview Terrace, Stornoway and sometimes at Tarbert.

We are currently in negotiations with the Health Board to have a renal unit on the island, and the provision of a visiting consultant for renal patients. This is progressing and we are hopeful of the outcome.

We promote the uptake of Organ Donor Cards, although we recognise that this is not everyone’s view—we respect that.

We are able to provide grants for renal patients and their relatives for sudden travel costs and small household items etc, that may be helpful for the well-being of patients.

We have access to national and world wide research information and can provide this and other related info such as special diet and fitness; booklets on what exactly is kidney disease and how it affects you and your family.

We are a registered Scottish Charity—No. SC 031520 and are affiliated to the National Associations.

If you require any information, or just want to chat to someone who knows what it’s like to be a patient or the relative of a patient, please contact us on 01851 705395; 01851 703837 or 01851 705188. You can also contact Peter MacDonald on 01851 700311 or peter.macdonald11@bopenworld.com (This article was contributed by WIKPA)

A user led **Carers’ Group**, which will meet on a monthly basis, at Grianan was set up at a meeting on 13th May. For further information contact the Community Care Forum (01859 502588); Alzheimers Scotland (70 2123) or Crossroads Lewis (70 5422).

THE CLYDESDALE BANK have introduced a new trust fund for Young carers in Scotland which will be administered by The Princess Royal Trust for Carers. The criteria is similar to *The Wooden Spoon Fund* in that awards will be granted to enhance the opportunities for educational attainment and to develop special skills. Contact the Highland Carers helpline on 08457 66 00 26.

“Making life easier: a carer’s guide to support aid and equipment” is an information leaflet produced by Carers UK. It provides information on where to find and fund equipment. If you would like a copy please contact them on 0141 221 9141 or by e mail to info@carersscotland.org.

CONTACT THE ELDERLY—a simple act of friendship

“Contact the elderly is a charity concerned to help relieve the loneliness felt by older people who have become isolated from the Community in which they used to be active. For many older people who can no longer get out easily on their own, loneliness is the worst of their problems. Having few or no friends or relatives nearby, they may miss company generally, but they may also miss the social contact they had through their work etc. It has been shown throughout the country that taking the elderly out from time to time helps them in many ways and I know of one lady who says that CONTACT outings ‘are better than all my pills.’

CONTACT offers lonely elderly people a monthly outing to different private houses for a chat and afternoon tea. I know that a lot is being done for the elderly in the area but we feel that there is scope for CONTACT beside what is already being done.

The volunteers who make up a Contact Group need only give one afternoon each month as a driver, or one afternoon a year as a host. They may derive as much pleasure from the friends they make among the older members, as well as the satisfaction of seeing what a difference the monthly tea party can make to the life of the older people. There are over 200 groups throughout the country, including 14 in the Highlands and Contact the Elderly is very keen to start new groups in any area where it is felt there is a need or a demand. In some areas there are variations on this type of outing, but the important factor is that they help to relieve the loneliness of older people.”

(This article was contributed by Alan Michael, Development Officer, 28 Culloden Road, Balloch, Inverness IV2 7HQ (01463 790410), who can be contacted if any person or organization is interested in starting a group or wishes more information on Contact the Elderly.)

ADULTS WITH INCAPACITY (SCOTLAND) ACT 2000

This is the law that helps people who are unable to make their own decisions. It came into force last year and affects anyone over 16 who is unable to make their own decisions. It deals with managing property, financial affairs and personal welfare including medical treatment. There are ways of preparing to deal with this situation by setting up ‘Power of Attorney’ in advance. This allows other people to make decisions on their behalf, subject to safeguards in legislation. The Act will have an impact on people who have a mental health problem, learning disability, dementia, an inability to communicate because of physical disability and acquired brain injury or stroke.

Those acting for adults with incapacity owe a duty of care to them and it is now a criminal offence to wilfully neglect that person. The Scottish Executive and Enable have produced leaflets and if you require more information please contact Highland carers on 01463 718817 or write to Highland House, 20 Longman Road, Inverness IV1 1RY.

INVALID CARE ALLOWANCE

From 28 October 2002, the upper age barrier for Invalid Care Allowance was abolished to provide all carers with fair and equal access to the benefit. Although the age barrier was removed, there was no change to the purpose of the benefit. It remains a non-contributory, non means-tested benefit and is not intended to be a wage for caring, nor a payment for the services of caring.

Other benefits still affect ICA—for example—it cannot be paid in addition to Retirement Pension. If the carer's pension is less than the rate of ICA, they will be paid a top-up to the ICA level. Carers entitled to ICA and on a low income may be able to qualify for the Carer Premium which is paid with income related benefits such as Minimum Income Guarantee and Housing Benefit. Some disabled people in receipt of income-related benefits get severe disability premium. If their carer gets ICA, the disabled person will lose that premium.

When the disabled person dies, entitlement to ICA continues for up to 8 weeks. This will help bereaved ex-carers to adjust and make plans for their future. The normal ICA rules still apply within the 8 week period except the bar on full time work and study. Other benefits will be affected by the overlapping benefits rules. For example, where the disabled person was a spouse and Bereavement Benefit is payable, ICA will not be payable.

The people most likely to benefit under the new rules are people on low incomes and carers (mostly women) who are on a reduced rate of Retirement Pension.

For more information contact your local CAB—Lewis 01851 705727; Harris 01859 502431; Uist 01870 602421; Barra 01871 810608.

Western Isles Concessionary Travel Scheme

The Travel Card is available free of charge to persons aged 16 & over and in receipt of higher rate mobility component of DLA as well as to OAPs. The holder, in either category, must have their sole or main residence in the Western Isles. Holders are entitled to the following benefits: **free** travel after 9.30am (Mon-Fri) & all day at weekends on any scheduled bus routes, post bus or ferry **within** the Western Isles. The holder is also entitled to either:

1 free return trip to the mainland per year; **Or** purchase a 6-trip ticket for half the normal price. For example a 6-trip ticket from Stornoway to Ullapool would cost £29.50 instead of £59.00.

For further information contact your local Social Work Department or Citizens Advice Bureau.

SHARED CARE SYSTEM FOR ALCOHOL/DRUG USERS

Mrs Shona MacLeod—on behalf of, and with the ADSAT (Alcohol, Smoking and Drug Action Team) - has been developing a 'shared care system for alcohol and drug users' in line with Government objectives.

Throughout the Western Isles a system will be put in place using referral forms, designated Lead Workers and Single Shared Assessment in order that alcohol and drug users may be given a well co-ordinated and needs linked service.

The new system is due to be implemented from April 2003 and training will be given in relation to the system in January 2003.

More information can be obtained from Shona Macleod who has an office at Dun Berisay in Stornoway. Telephone 01851 701585.

ARE YOU LOOKING AFTER SOMEONE?

Over 600,000 people in Scotland are carers—an amazing 1 in 8 of us! Do you look after someone who is ill or disabled, or simply could not manage without your help? Do you help someone with washing, feeding or dressing? Do you collect medicines for people and make sure they take them on time? Do you collect benefits or pensions for someone, pay their bills or help them manage their money? If you **answered yes** to any of those, **then you are a carer.**

A carer is someone of any age, including children and young people under 18, who looks after a relative, partner or friend. It may be full time, part time or just now and then. You may not see yourself as a carer. You may feel that you are simply looking after your husband/wife, partner, child, relative or neighbour.

Help is available. You and the person you look after may be able to get help from your local council, NHS or voluntary organisations. You may be able to get help with household tasks or caring for the person you look after; information on benefits and other financial help that is available; equipment or adaptations to your home to make caring easier; or a break from caring. You can ask your local authority to make a **community care assessment** with the person you care for to find out what help they need. As their carer, you will also get a chance to say what you feel they need. New laws mean that you can also ask your council for a separate **carer's assessment**, at any time, of your situation as a carer. This will allow you to say what support you feel you need to help you care. You may not need help at the moment, but you may want to know about your rights. You may just want advice or information, or to meet other carers.

You can call the **NHS Helpline 0800 22 44 88**, for information about help and support for carers in your area. Calls are free, and lines are open from **8am to 10pm** every day. The Helpline can : help you find local organisations that support carers; put you in touch with someone in your local council; or give you general information on financial help and other help that is available to carers.

There are local organisations which give practical support such as day centres and day clubs, others which provide respite care and yet others which provide information etc. Concise details are contained in the Western Isles Directory of Care Services which is available free from the Western Isles Community care Forum.

At a national level, **The Princess Royal Trust for Carers** can be contacted on **0141 221 5066** and **Carers Scotland** on **0141 221 9141** *or* **Carersline: 0808 808 7777 (Monday to Friday 10am to 12 noon and 2pm to 4pm.)**