We Care

The newsletter of NSF SCOTLAND Summer 2004

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In this issue

The editor wishes to point out that the views expressed in this Newsletter are not necessarily those of NSF (Scotland)

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Our mission statement

NSF (Scotland) aims to improve the wellbeing and quality of life of those affected by schizophrenia and other mental illnesses, including families and carers.

The National Schizophrenia Fellowship (Scotland) is a National Charity concerned with schizophrenia and allied illnesses. We achieve our mission through campaigning, education and provision of practical help, support and advice.

From the Chief Executive

Welcome to NSF (Scotland)'s Summer issue of 'We Care'. We always welcome feedback about the Newsletter. These might be comments about some of the articles and topics featured in its pages, or suggestions about what our readers (especially service users, family members and carers) would like to see included in future issues. If you want to do this, please contact Ian Harper at National Office.

Over the past few months, NSF (Scotland) has been conducting its three-yearly Strategic Review. The findings from this Review will inform the development of our new Forward Plan, which will run from April 2005 to March 2008. As part of the Review process, I visited as many of our projects around Scotland as possible during the first half of this year. The subject of physical healthcare came up in many of my discussions with service users, carers and staff. There are many aspects of concern about the physical healthcare of those who use mental health services. On pages 6 and 7 we have included contributions on this subject from our Public Health Adviser, Cameron Stark; David Bolger, Head of the Mental Health Division at the Scottish Executive; and David Law, who in 2003 undertook a pilot Health and Well-Being study at the Riverside Resource Centre in Partick, West Glasgow. These contributions raise serious concerns but also grounds for optimism that things can be improved. NSF (Scotland) would like to see the services provided during the Riverside pilot study being made available to all mental health service users in Scotland.

Discussions are currently underway within the NHS about changing the ways in which people's medical records are kept and accessed. The overall aim of this is to provide more effective communication among those involved in the care and treatment of patients. While this is laudable, it has caused concerns for some mental health service users about how many people might be able to access their records in the future. There are also concerns about how factual accuracy can be ensured. Rosemary Carter, a longstanding member of NSF (Scotland), describes some of her concerns in her article on page 4.

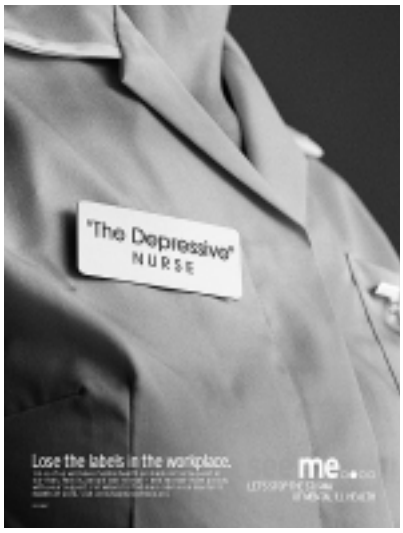
Finally, here are some dates for your diary!

Thursday 16 September	Re-launch of NSF (Scotland) website: www.nsfscot.org.uk
Saturday 30 October	Members' Event and AGM
Wednesday 1 December	Conference on Early Intervention (co-hosted with 3 partner organisations). More details will be sent out soon.

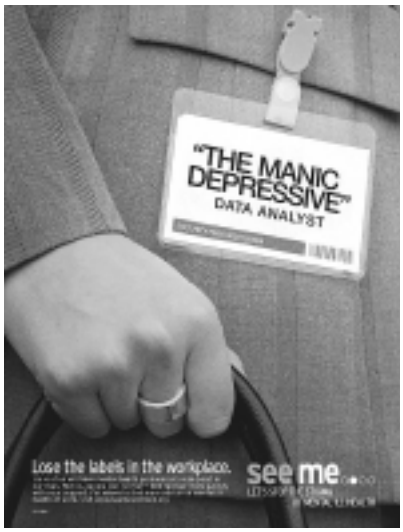
Mary Weir

‘see me’ Sets Its Sights on Stigma in the Workplace

Getting and keeping a job is high on most adults’ priorities. Having a mental health problem can, however, make working life difficult, sometimes because of the effects of mental ill-health but too often because of negative attitudes from colleagues or managers.



For that reason, ‘see me’ has launched a campaign to target work-related stigma. The campaign has been developed in consultation with employees, managers and service-users across Scotland. The main message is that having a diagnosis of mental ill-health does not stop someone being a valuable employee.



Campaign posters and postcards have been circulated to workplaces right across Scotland, urging people to ‘Lose the Labels in the Workplace’. As well as producing materials, ‘see me’ is running a radio ad campaign and providing information on the website. These efforts are backed up by intensive press work highlighting the impact of both good and bad practice on the lives of individuals who have experienced mental ill-health.

For more information or to order campaign materials, visit **www.seemescotland.org**

Information sharing

Speech given by Rosemary Carter
at "Improving Mental Health Information" event on 19 February 2004

I am a user of services and am opposed to data-sharing of psychiatric records.

The thoughts that are shared with you are backed up by a number of mental health professionals and a growing number of mental patients.

First, the degree of trust between the psychiatrist or CPN and the mental patient is at stake.

Psychiatric records are not ordinary medical records. Psychiatric records are not discussing earache or appendicitis. Psychiatric records are discussing people's private lives.

One can think of many sensitive topics that are discussed by a patient in psychiatric care: fears, phobias, addictions, loss of any kind, work, family life, sexuality, accommodation circumstances, friendships, paranoia and more. It would undoubtedly make me paranoid to discuss these things with a mental health professional knowing that the information is going to go down on multiple screens. I will hold back from discussing these things and will not benefit from the treatment that would be needed.

Next, we are told that the patient is entitled to have a choice in whether or not to allow his or her information to be shared with other health professionals: but in the event that the patient refuses to allow their records to be shared on multiple screens their care will be limited and the patient will not be able to get the full treatment. So it is Hobson's choice.

We are told that the patient will be able to have a copy of information that is recorded about him or her: but the patient will never know if it is a full and complete copy or whether information has been withheld.

Fraud does exist. Computers can be hijacked. Only last week it was announced on the news that a Microsoft Windows blueprint had found its way onto the Internet.

We are told that it will be possible to correct errors that are on multiple screens and that there are four stages of complaint: first to approach the CPN, psychiatrist or data controller. If that doesn't work one complains using the National Health Service complaints procedure. If that doesn't work the data subject can approach the Information Commissioner: and if that is unsuccessful the data subject can go to court to have the error corrected.

Undoubtedly to follow these procedures would not only destroy the clinical relationship between the mental patient and the psychiatrist or CPN: but also this would destroy the mental patient's own mental health. No patient would survive the stress that would be created by taking even one of these steps. In addition, the mental health professional who made the notes may well have left his or her job and gone to another part of the world.

We are talking about people's bereavements, people's fears and people's nightmares.

Psychiatric patients have little enough privacy as it is, but to display their private lives on multiple computer screens will take away the last vestige of dignity from mental patients and drive many into depression and even suicide.

NSF (Scotland) would welcome views on this issue, both for and against.

Health Warnings!

Cannabis and Psychosis

NSF (Scotland) is concerned that people may be regarding cannabis as a risk-free drug following changes in its legal status earlier this year. In January cannabis was reclassified from a Class B to a Class C drug, suggesting it is a 'least harmful' drug, even though possession of it is still illegal. Recent studies have shown that use of cannabis is far from harmless and that there are associated health problems. In particular, there is strong evidence that using cannabis is a risk factor for schizophrenia.

A study by the Institute of Psychiatry has shown that people using cannabis in adolescence are twice as likely to develop psychosis in adulthood than people who did not use it. The risk goes up to four times if young people started using cannabis before the age of 15. Heavier usage also carries a greater risk.

A Swedish study has also found that evidence shows that using cannabis doubles the risk for schizophrenia and that the risk increases in proportion to the amount of drug used.

Studies in other countries have confirmed these findings. The full relationship between cannabis use and psychosis is, however, complex and further research is required into areas such as:

- The mechanism of why cannabis use causes psychosis
- Cannabis use worsening or altering the course of a mental illness
- Cannabis use leading to relapse

NSF (Scotland) is not suggesting that cannabis use is a *cause* of schizophrenia. The evidence to date, however, gives strong indications that for people at risk from psychosis, cannabis use can be a powerful trigger for onset of illness and/or relapse. Not enough is yet known about the causes of schizophrenia for us to know who is or isn't at risk. Until any evidence to the contrary shows otherwise, we strongly recommend that those using cannabis, or considering using cannabis, take the above information into account.

Medication over the internet

NSF (Scotland) shares the concern of many agencies about the availability of medications for sale over the internet. These range from the British Medical Association to the pharmaceutical companies themselves.

The United Nations have urged governments to crack down on this trade, but the problem, as stated by the Medicines and Healthcare products Regulatory Agency (MHRA) in the UK, is the largely unregulated nature of the internet. Many internet pharmacies are legitimate and are licensed to provide medications on prescription, but there are a growing number that operate illegally, selling drugs to anyone willing to pay for them.

Almost all medications can be bought from internet pharmacies, but there is no guarantee that these are genuine, and there is a danger of drugs being tampered with or counterfeit versions being provided. Medications, other than those available 'over the counter', in any case should not be taken without a prescription from a qualified healthcare professional. There are risks, as stated by the MHRA, of members of the public being supplied with medicines that are not safe or are unsuitable for them.

Prescription only medicines should only be taken in consultation with a healthcare professional in order that the appropriate product is prescribed and side effects monitored. There can be also be interactions with other medicines, so that NSF (Scotland) urges people to consult with their doctor to gain a prescription rather than buy medication directly from an internet supplier.

'Poor physical health affects our mental health. Poor mental health affects our physical health.'

The above statement from a service user highlights one of the many aspects of physical health and healthcare affecting people with mental illness. NSF (Scotland) has growing concerns about these issues. In the following two pages we have invited contributions from Cameron Stark, David Bolger and David Law which touch on different aspects of this important matter. *We invite our readers to send in their views and comments about their experiences of physical health issues.*

HEALTH OF PEOPLE WITH SERIOUS PSYCHIATRIC ILLNESSES

Dr Cameron Stark is Consultant in Public Health with NHS Highland and is NSF (Scotland)'s Public Health Adviser. Below, he describes some recent research into the mortality rates of people discharged from long-term psychiatric care in Scotland between 1977 and 1994.

This section describes Scottish work on the health of people with serious psychiatric illnesses. Work in Scotland has found that people with serious illness often have poor diets, and smoke more than average. Our work tried to find out whether this was reflected in higher death rates from physical illness.

We used the information held by the Information and Statistics Division (ISD) of NHS Scotland to identify people who had been discharged from psychiatric hospitals in Scotland between 1977 and 1994, after a stay of at least twelve months. This was intended to identify people with severe illness. We then checked to see if the person had died, using death certificate information. This included deaths only in Scotland, so might underestimate the true number of deaths. The study used identifying numbers provided by ISD, rather than names, so we had no access to the details of individual people.

We took account of the expected death rates in people of the same age and gender in Scotland. A total of 6,776 people met the criteria. The single largest group of people had a diagnosis of schizophrenia (2,799 people). In the whole group of 6,776 people, 1,994 (29%) had died by the end of the time period. This was 732 more deaths than would have been expected from Scottish averages. 197 of these extra deaths were from suicide, murder, accidents or undetermined causes. The remainder, the majority, were from natural causes of death. Deaths from respiratory disease were four times commoner than expected. Cardiac related deaths were the single biggest cause of deaths, and were about 50% higher than expected.

We concluded that, while suicide is important in this group of people, natural causes of death account for a higher proportion of extra deaths. This might be because of the higher risk factors (smoking, diet), because of reluctance to seek treatment, because of poorer treatment, or because of a combination of all three. Our results do not answer the question of why the death rate is higher, but they do confirm that increased rates exist.

The full research report was published in September 2003. It is entitled 'Mortality after discharge from long-term psychiatric care in Scotland, 1977-94: a retrospective cohort study' and can be found at http://www.biomedcentral.com/1471-2458/3/30. Alternatively, please contact National Office if you would like a copy.

HEALTH AND WELLBEING CLINIC

David Law, Community Psychiatric Nurse, describes a pilot study conducted at the Riverside Resource Centre in Partick, West End of Glasgow.

A pilot study was initiated to consider a proposal to provide a comprehensive service for clients with major mental health problems living within their communities – to improve both their mental and physical health, promote and continue inter-agency links through health promotion and education, and to assess the impact of the side effects of antipsychotic medication. A total of 35 clients were invited to attend two scheduled sessions and an excellent turnout suggests the proposed service would be well used.

The clients were aware of the importance of general good health, but half were inactive and a third were overweight. Half smoked, half had elevated blood pressure and cholesterol levels, and one in five's alcohol consumption was higher than the national average.

The enjoyment of good physical health and a sense of well-being are very important to those who use mental health services and the findings of this pilot study support the proposal that a Health and Wellbeing Service should be introduced as a core part of community mental health services. Regular monitoring would benefit the general health of clients. And contact with mental health services offers the ideal opportunity to encourage them to review their lifestyle choices, while monitoring key indicators of their general health status.

LINKS BETWEEN MENTAL AND PHYSICAL HEALTH

David Bolger – Head of Mental Health at the Scottish Executive Mental Health Division – highlights the links between physical and mental health, and describes some measures being taken by the Scottish Executive to address some of the problems.

On average, people with long term mental health problems are likely to live 10 years less than others. This inequality is being addressed in a number of ways – for example, by addressing the poverty and social exclusion issues which can be both a cause and result of mental health problems in all areas of life from housing and employment to improved access to general healthcare.

In health care generally, greater account needs to be taken of people's mental *and* physical health needs, while promoting health awareness messages aimed specifically at those with long term mental health problems – in regard to such matters as diet, exercise, sexual health, stopping smoking and tackling alcohol and other substance misuse. Community Health Partnerships offer an opportunity to address people's physical *and* mental health needs. Physical health impacts on mental health and vice versa. More attention can be given to health screening and encouraging those with mental health problems to develop physical activity as one aspect of their overall care and treatment. There is an increasing number of examples of "good practice" in secondary care mental health services. Local areas should adopt and develop these models so they become the norm rather than the exception.

The Scottish Executive is supporting a range of actions to help address these issues. These include financial support for a stopping smoking project in the State Hospital where 90% of patients smoke; the development of a guide for primary care providers on responding to the physical health needs of people with mental health problems; and a paper on social prescribing, looking at evidence and examples of practice across Scotland. At the same time, the Scottish Recovery Network will also be exploring in more detail the importance of physical health.

The Executive is keen to hear about examples of good practice from around Scotland. With the focus of this year's World Mental Health Day in October on the links between physical and mental health, this is a good opportunity to draw attention to this important issue.

STRANGER HOMICIDES NOT LINKED TO MENTAL ILLNESS

We print here a summary of a study which reviewed the background of those who had committed homicide on people unknown to them over a 30 year period. The study was conducted in England and Wales but the conclusions would equally apply to Scotland. While finding that such stranger homicides have greatly increased over the years there has not been a corresponding increase in the number of people committing such acts who had been in receipt of psychiatric care. In total numbers they actually constituted only a small fraction of the perpetrators and those with a diagnosis of schizophrenia a smaller fraction still.

The findings are consistent with other research in recent years, including the National Enquiry into Homicides and Suicides, showing that the public are not at risk of attack from people with mental illness.

Jenny Shaw, Senior Lecturer in Forensic Psychiatry at Manchester University, has stated in the British Medical Journal that perpetrators of stranger homicides - where the victim is unknown to the perpetrator - are most likely to be committed by young men with a history of alcohol or drug misuse, rather than people suffering from a mental illness

In the past 30 years, the annual number of convictions for "stranger homicide" in England and Wales has increased more than threefold. In the same period, the number of psychiatric hospital beds has more than halved. And some journalists have sought to link these factors together, with several cases of homicide by mentally ill people being sensationally reported as failures of the policy of "care in the community".

As a result, public fear of being a random victim of violence by people with mental illness living in the community seems to have increased. However, the results of a recent study show that while stranger homicides have increased both in number and as a proportion of all homicides, no increase was found in the number of perpetrators placed under a hospital order after homicide.

Stranger homicide is more often associated with alcohol and drug misuse than with severe mental illness, say the authors of the report. This is also true of homicides where the victim is known to the perpetrator. Almost all stranger homicides are committed by young men, and the victims are usually male. Most seem to occur as a result of physical fights or attacks.

At the same time, however, the authors point out that failings in mental health care have contributed to some individual cases, and steps should be taken to prevent this. For example, mental health services should work to prevent the loss of contact and non-compliance with treatment that frequently precede homicide by people with severe mental illness. In the 30 year period studied, of the 37 perpetrators of stranger homicides (out of more than a thousand cases) who had ever been in contact with mental health services, only 10 had received a diagnosis of schizophrenia. Of these, eight had been in contact with services in the year before the homicide; two in the previous week.

More information at:
http://bmj.com/cgi/content/full/328/7442/734
BMJ 2004; 328:734-737 (27 March)

Update on ...

THE MENTAL HEALTH (CARE AND TREATMENT) (SCOTLAND) ACT 2003

PROGRESSING TOWARDS IMPLEMENTATION

Most parts of the new Act will come into effect in April 2005. The Scottish Executive is working to ensure that all the necessary measures are in place by then to enable full and proper implementation. Many organisations outside the Executive have been assisting in this process. To date, NSF (Scotland) has been involved in the following ways:

- Membership of the Mental Health Legislation Reference Group (MHLRG) and through that;
  - Membership of the Monitoring, Assessment and Research sub-Group
  - Membership of the Tribunal sub-Group
- Membership of the Guidance, Training and Information sub-Group – and through that;
  - Membership of the NHS Education Scotland Reference Group – which is devising training materials for front-line NHS staff
  - Membership of the Communication Working Group, devising information guides for service users and carers about various aspects of the new Act.

NSF (Scotland) has also responded to Volume 1 of the Draft Code of Practice and will be responding to Volumes 2 and 3.

Two carers from NSF (Scotland) – Carolyn Little and Penny Duce – recently became members of the MHLRG in their own right, bringing a carer perspective to the work of that Group. The Working Group developing Standards for Mental Health Officers has also benefited from the input of two carers recruited via NSF (Scotland) – Elinor Dowson and Agnes Ritchie.

Because of the volume of work outlined here it isn't possible to report back on all of these activities – but readers can be assured that the views and concerns of our community of interest are being kept to the forefront in all of the above.

ACTION NEEDED TO IMPROVE CARE FOR PEOPLE WITH SCHIZOPHRENIA

On 14 June, NHS Quality Improvement Scotland (NHS QIS) launched the report of its review of NHS services for people with schizophrenia in Scotland. The report marks the culmination of a three-year enquiry into the performance of these services, linked to the Clinical Standards for Schizophrenia. It found that there continues to be far too much variation in the standard of care offered across the country.

Some progress is being made in improving services and there are many examples of good practice and innovative developments across the country. However, service development continues to be hampered in many places by a lack of accurate record keeping, poor continuity of care, incomplete care planning and insufficient support for service users and carers.

The Chairman of NHS QIS, Lord Naren Patel, commented:
'...It is very disappointing that recommendations made in 2002 have still to be implemented in many parts of Scotland. It is vital that action is taken now by those responsible for mental health services to improve the care of people with schizophrenia. NHS Quality Improvement Scotland intends to target efforts on mental health services and will continue to monitor progress across Scotland to ensure that services improve.'

Sandra Dow, a carer who has been involved in the review process and who has also served on the Mental Health (Schizophrenia) Project group of NHS QIS, said at the launch event:
'When I became involved, my aim was to get a better quality of life for my son and others like him. This hasn't happened yet. The Standards are good, and achievable. They are not yet achieved. This National Overview is well written, honest, accurate and optimistic. It gives good recommendations, and should be read by everyone.'

NSF (Scotland) will be asking at regular intervals what NHS QIS can tell us about improvements identified nationally as a result of its monitoring activities. The local reports give useful information, along with clear recommendations for improvements in the areas concerned. For anyone wishing to make representation about the need for service improvements in their own locality, the local reports provide a useful reference point.

The National Overview Report, along with local reports (by Trust area), can be obtained from NHS QIS by phoning 0131 623 4300, or from their website: www.nhshealthquality.org

SCOTTISH SCHIZOPHRENIA OUTCOMES STUDY

Professor Robert Hunter, Rosie Cameron and Catherine Divers describe an ongoing project to collect health data on people with Schizophrenia living throughout the country, which has already provided tangible benefits for Scottish Mental Health Services

The Scottish Schizophrenia Outcomes Study (SSOS) is a three-year national clinical effectiveness project funded by NHS Quality Improvement Scotland. The main aim of the study is to collect pragmatic mental health outcome data on people with schizophrenia living throughout Scotland.

Local NHS organisations have been very helpful with SSOS, forming part of their Clinical Effectiveness teams. Every NHS Trust in Scotland is participating in the study, so it covers urban, rural and remote communities. This has been an opportune time to undertake our study, in regard to the recent Report on Schizophrenia Standards from NHS Quality Improvement Scotland.

An important element of the study has been to carry out training for mental health professionals in the use of the core outcome measures being utilised in the study. These are recorded in two forms. HoNOS* is completed by the clinician, while AVON** is completed by the service user. In this way, both perspectives are accommodated.

In Phase 1 of SSOS, 1014 participants were recruited from across Scotland. The study is now nearing the end of Phase 2 (second assessment), and to date the return rate for Phase 2 follow-up assessments is 80%. Phase 3 is due to begin later this year.

An important component of SSOS is to hold annual national meetings during the three year project, to provide a forum for feedback and discussion for keyworkers and project members. The first national meeting was held in June 2003 and 110 people attended, including representatives of service users and carers. The key focus of this meeting was to share good practice in the use of outcome measures from mental health services throughout Scotland. The conference was a great success and provided a positive forum to support keyworker clinicians, re-emphasise the objectives of the project and facilitate the networking of new ideas. A second national meeting is currently being planned for September 2004.

As well as the 1014 people with schizophrenia taking part in the study, a total of 627 keyworker clinicians are registered to date, of which 370 are currently supporting the study and following up participants in Phase 2.

Scottish Mental Health Services are benefiting from participation in SSOS in a number of ways. Service users are able to express their own concerns through the use of AVON. Staff have become more aware of mental health outcome measures. It has encouraged the use of outcome measures by staff and service users in routine clinical practice. And it has prompted dissemination of local initiatives in Mental Health at local and national meetings.

The SSOS project is very grateful to NHS Quality Improvement Scotland, NHS organisations, voluntary organisations including: SAMH, Richmond Fellowship and NSF (Scotland), other non-NHS sponsors, keyworkers and service users, for their continued help and support in the study

*HoNOS: Health of the Nation Outcome Scales are used by clinicians to rate various aspects of people's mental and social health.
** AVON: the AVON Mental Health Outcome Measure is designed for service users to self-report on outcomes.

Around the Country

Making a Difference in Tayside

Jane Withers, our Involvement Worker with Tayside Carers Support Project, is confident that we can improve the quality of Mental Health Services.

Our slogan is "Together We Can Make a Difference" and a recent success shows just how much we can achieve by adopting this approach. A Mental Health Review across Tayside saw the Health Board engaging with service users and carers concerned about the possibility of acute beds being centralised in Dundee, which would have meant folks from Perth and Kinross and Angus having to travel many miles to visit their loved ones.

With our support, the carers made a strong case for keeping services local – and won!

We work hard to build good working relations with service providers, while raising their awareness about difficulties such as confidentiality issues from the carer's point of view. Some carers are especially interested in the educative side of Involvement and we have plans, in conjunction with service user Involvement Groups, to expand the work already happening by taking part in training courses for various health professionals. Cathy Hamilton, Project Manager, has built up a tremendous network with service providers and is often invited to take part in training events in other parts of the country. Carers accompany her to tell their stories, and the feedback we receive affirms how valuable this process is. Together, we *are* making a difference...

Edinburgh Group

The Edinburgh Group celebrated their 30th anniversary with a meal enjoyed by past and present members of the Group in ... Before the meal Professor Owens from the Royal Edinburgh Hospital set the scene by giving an entertaining presentation of his views of developments in the field of psychiatry over the past 30 years. Many changes in attitudes and treatments have taken place over this period. Some of the longer standing members of the Group could remember the time when they were given to think that they were to blame for their relatives illness with service users themselves led to believe that this was an illness for life.

Ongoing research and improved techniques for gaining images of the brain have improved our understanding of schizophrenia and better medications are leading to improved quality of life for many people.

Two longstanding members of the group

Professor Owens

Around the Country

Garden Project, Kaleidoscope

The Kaleidoscope Garden has provided interest and a focus for summer activities for some years now. This year a serious attempt has been made to develop and formalize this interest into a project. We meet twice a week and have developed a project plan and programme to guide our progress each week.

We believe that people can benefit greatly from having a more active role in developing their surroundings, and in turn will benefit from having a better garden to enjoy and inspire.

We have a substantial number of projects being developed. These include a herb garden, vegetable garden, a memorial bird bath to one of our clients who recently passed away, planting beds and pots, and painting fences, pots and posts with creative designs. There are also interpretation and many art and educational based projects.

The group is led by Gerry Kerr, and facilitated by two staff members from Kaleidoscope. Anyone interested is made welcome.

The new improved herb garden.

Recently we have received a generous donation of £500 from the League of Friends at the Crichton Royal Hospital to further our projects in the Kaleidoscope Garden.

The Arches, Banff

The Arches Centre in Banff said farewell to the manager, Jennifer Archibald, who had been with the project for many years. There was some sadness but Jennifer was wished well for her new career.

Jennifer, second from left, with staff from the Arches.

Cotton Club, Castle Douglas

Creative work has taken place in Castle Douglas where members of the Cotton Club organised an art exhibition at the Castle Douglas Art Gallery. The front page shows one example of the work and shown right is the exhibition itself.

Are you a member? If you are a carer, service user or professional or someone interested in mental health issues, you can help to support us by joining NSF (Scotland). Membership entitles you to become involved in the work of the Fellowship and receive our quarterly newsletter. Alternatively, you can express your support by becoming a Friend In Deed of the Fellowship. Further details can be obtained from National Office.

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