

Grapevine

The background of the cover is a painting. It depicts a woman in the foreground, seen from the side, wearing a vibrant red coat and a matching hat. She is walking across a grassy area. In the background, there is a large, multi-story building with several arched windows and doorways. The overall style is somewhat impressionistic with visible brushstrokes.

Magazine of Rehab's Mediability Programme

May 2005

Down
but
not
out

A personal account
of homelessness

**INSIDE: Here Comes the Sun; Conjugal Wrongs; Lives Less Ordinary;
The Hand that Lays the Table; Sticks and Stones May Break My Bones**



Grapevine Editorial

Mediability is a unique applied communications training programme set up by the Rehab Group in response to the lack of people with disabilities working in the Media. It is a distance learning programme which offers training and employment opportunities in journalism and media to people with disabilities.

The Grapevine magazine has been produced every month for the past two years as a platform for the students of Mediability to gain experience in print journalism. It has been included within Rehab News on this occasion to reach a wider audience for our work.

Since the magazine's inception, we have covered all aspects of journalism from the very serious to the more light-hearted and entertaining. It has become clear over time that Grapevine was evolving as an issue based publication and it is for this reason we have decided to concentrate on the more serious topics for this special edition.

If you feel you would like to comment on any of the topics covered in this edition please feel free to contact me by email
jbmedia@eircom.net

Jennifer Banks

Cheaper flights and the increasing ease of travel has opened up the opportunity to take a foreign break to everyone... as long, of course, as they don't have a disability, says Jacqueline Johnston-Fagan.



Here Comes The Sun

...as long as
you're not a
wheelchair user

Fancy a holiday in the sun? Imagine warm, sultry days lounging by the pool sipping a Margarita safe from the ravages of a 'mild' Irish spring. You'd think it would be easy to make a call or visit a travel agent to book a week of intensive body lobstering or tanning (depending on your skin type!). In truth, it is easy for most but chuck a wheelchair into the equation and you're suddenly trying to board a very different Boeing 747.

A random sample of travel agents and tour operators revealed that, generally speaking, people with disabilities are not catered for in any meaningful way. If pushed, the agents will make enquiries to see if particular blocks of apartments have wheelchair access, but there doesn't appear to be any packages tailored specifically to meet the needs of disabled holidaymakers. Speaking to a staff member at a branch of one of the country's most popular travel agencies revealed that, once again, disabled people are being treated unequally. She politely said that she knew of "two or three apartments in one resort that have wheelchair access". During a conversation punctuated with a lot of "ems and ahs", she admitted that they had no packages available suitable specifically for disabled clients. She suggested contacting a tour operator, as it was their job to put the packages together and then pass them on to travel agents to sell them.

The same story emerged when another well-known travel agency was contacted. The assistant was apologetic and admitted that following an enquiry from a group of disabled customers a while ago, she "rang

around all the tour operators in Ireland, but not one had a package put together specifically with disabled people in mind". She reiterated that agents only sell what tour operators put together. There was a distinct whiff of passing the buck in the chilly Irish air. As she recounted an experience of one particular disabled client who went back year after year to the same resort that met his needs adequately, it became apparent that if you have a disability, your choice of holiday destination or resort is severely limited.

Alarming, another representative in yet another well-known agency revealed the main reason for their reluctance to advertise or promote facilities for disabled sun-worshippers. "For legal reasons, we're slow to say if a property or facility is disability-friendly in case the client goes there and it isn't. Then our company would be liable". Don't most travel agencies/tour operators send staff out to these resorts to check them out in advance? It would hardly present a back-breaking task to check their suitability for disabled clients also.

The last port of call was a tour operator. Expectations were high. "I could do you a nice trip to Lourdes" was not an option. Disappointingly, the outcome was the same: travellers packing a wheelchair in addition to their suitcases are way down their list of priorities. When pressed for further information about holiday facilities for disabled people, the rep suggested, "Try the travel agents, they should know"! The assistant disclosed that her mother was disabled and found it "very difficult" to find suitable holidays. She also said that to the best of her knowledge there were no Irish tour operators specifically geared towards arranging holidays for disabled people. When I suggested that it would not only be more equitable to offer tailor-made packages but it would also make good business sense, she agreed but added that plans to do so were not in the pipeline at present.

There are travel agencies and tour operators in the UK that specialise in organising holidays and travel generally for people with disabilities. A trawl through the Golden Pages revealed no such Irish companies. In the section 'Disabled Persons Products & Services', there are many companies offering Stanna Stairlifts, walk-in showers and electric beds. Perhaps disabled people are only interested in going up and down stairs, washing and snoozing their heads off! Need a holiday? Pah, some think a modified toilet seat might be more appropriate.

Jim Murray **tells the chilling story of a battered wife who finally found the strength to escape her brutal tormentor**



Conjugal Wrongs

“**The sister came in one night with a man and it was the proverbial love at first sight for Priscilla. She and Thomas sat up all that first night and talked. They had so much in common.**

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Priscilla grew up in a large town on the east coast. In a family of sixteen, life, to say the least, was difficult. It was especially so since her father had a 'fondness for drink'. Perhaps, her father drank due to the anguish of losing three children to that relentless creditor, Death. But, her father was, as far as all were concerned, an alcoholic. He would shout and roar, but he was not violent. There was much sorrow, yet Priscilla has many happy memories of childhood. They were a big family and there were often lots of laughs. From her experience, she says, "One thing I swore I'd never do was to have an abusive husband or if I ever had kids to never let them feel the way I did when my father was shouting".

Priscilla was now a 20-year-old and had a son by a boyfriend. She was living in a small bungalow with her sister. The sister came in one night with a man and it was the proverbial love at first sight for Priscilla. She and Thomas sat up all that first night and talked. They had so much in common. Priscilla never made the connection then that the man on the couch beside her was the same person who had beaten up her former boyfriend's sister. The clues were there to see. But love is blind, and the excitement of a new romance can dim the connections of memory. She made the connection some time later when Thomas was in the process of battering her around the kitchen. He told Priscilla: "I only married you to spite her", referring to his former girlfriend.

"That night," Priscilla recalls, "he went

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home and said his mother gave him a choice because I had a child out of wedlock. She thought I was a bad girl, but I wasn't, I worked hard for my child. I never went out; my life was devoted to my son. When I came home from work that evening my sister said that Thomas was in the bedroom and all his stuff was with him. He said my mother threw me out and she called you the worst of names. I later found out that this was untrue."

From that day they lived together: "To begin with he was great fun, he was funny, and he was great with my son. There were days I didn't want to go to work. Thomas couldn't do enough for me; he always told me how much he loved me. I always felt that since I had come from a big family that I needed to be loved."

Then things began to change from dream to nightmare when Priscilla became pregnant with Thomas's child. Jekyll became Hyde one night during the fifth month of her pregnancy. He came home from the pub, entered the room and without saying a word he head-butted the heavily pregnant woman. Priscilla was in shock. "Nobody had ever hit me before," she said. She walked in a daze into the bathroom where she hit the window in sheer temper. But in her confusion her hand went through the glass five times. This was the beginning of her silent rage, she was now in the hands of an abuser:

Deep inside Priscilla knew this, but rather than face the reality of her situation she hit out. The blood squirted onto the ceilings and walls, in fact 'everywhere'. She collapsed and when she came around she could hear Thomas saying in her ear: "Don't tell them I hit you". Those words struck fear into her very soul and sealed her fate for now.

Priscilla was taken to hospital where the doctors presumed that she had made a suicide attempt. They wanted her to be admitted into a mental hospital. But she refused. He swore he'd never do it again. In her heart she knew those words were untrue but it is easier to believe than to accept she was being lied to. But three weeks later he began binge drinking. "And believe me, I got more clouts in those three weeks. So many people had warned me not to marry him and I wanted to prove to them that I was right. You



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Priscilla was taken to hospital where the doctors presumed that she had made a suicide attempt. They wanted her to be admitted to a mental hospital. But she refused.

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couldn't even see the bruising. In the beginning he would thump me in the stomach and kick me in the back so you couldn't see the marks."

Keeping the results of his violence unseen was Thomas's way of pretending he had done nothing wrong. If you don't see it it's not there! Even so, the violence was becoming obvious to others. Priscilla's five brothers 'literally' wanted to kill him, but she stood up for him. That's when her family turned against her. She continually made up excuses for him. Naively, she thought that she could change him. For most women in violent relationships it is easier to believe that you can

change the man when in reality it is you who must change and get out while you still can.

Things settled down for a while as the family grew and moved to a new and bigger house. But Thomas began to disappear for periods of time extending to three or four days. He made up scarcely plausible excuses for his absences; the reasons became ever less credible. Suspicions were multiplying in Priscilla's mind.

Then Priscilla found out when one night after she went home early from a birthday party, Thomas had slept with another woman. He flatly denied it even when she brought him up to the woman's front door:

"The last thing I said to him before knocking at the door was, "Are you going to tell me the truth?" He replied, "I wouldn't even bother knocking on the door." The girl admitted the wrong. Priscilla knew that his lying was now pathological. She walked from the door in total shock. The abuse was now total and the hurt enormous, as it seemed that Thomas had no feelings at all for anyone. But worse was to come.

Things returned to normal for the next three years when Thomas gave up drink. But the old pattern of abuse reasserted itself after this relatively calm period. Social workers and Gardaí were powerless as Priscilla refused to bring charges despite being raped within the marriage. Priscilla's eldest son saw the rape and she feels it has left a mark on him. The final straw came when he pummelled her stomach whilst pregnant with her last child. He threw her on a couch and said, "I'll beat the little bastard out of you". It was during this beating that Priscilla got the strength to leave him; motherly instinct overcame shame for it was the shame of having to admit that she had put up with his violent behaviour for so long that had trapped her in this hell.

The couple have now been separated for three years. He rings occasionally and taunts her. Nowadays, Priscilla lives in a suburb of a large town. Her children are everything to her. Gradually she is gaining the confidence to look forward again. She is now actively seeking work. The conjugal wrongs have faded in her mind but will be ever present in her soul, as Priscilla closes the door on a romance with no love.

Sean Richardson **writes about disabled people who in very different ways showed the world they were made of the right stuff**



Lives less ordinary

What type of hero must we look for today? Where is the leader who will pull us back from the abyss? The man or woman, who will be justifiably lauded as those of yore.

The people who can make us feel human again and fit for the fight. Who will lift us out of mediocrity and make us relate great deeds and feel better for knowing them. What examples are the children and teenagers watching these days? Our TV screens are filled with vacuous nonentities who cannot manage a coherent sentence and are immediately forgettable. The tabloids (and a few broadsheets) are more and more filled with witless drivel about 'celebrities' who, if there were justice and good taste, would not be allowed into the lowest den of inequity.

Franklin Delano Roosevelt did it all. He served three terms as President of the United States, saw his country safely through World War II, managed to have an extra-marital affair with his wife's social secretary and entered the pages of history. He had polio and had to use leg braces and a wheelchair. Nobody questioned his ability to do all this. In fact, America was largely unaware that he had polio – or a mistress, although the First Lady, Eleanor, had a good idea.

Douglas Bader was a reckless driver (which caused the accident that lost him his legs), a courageous and ruthless man who became a fearless fighter pilot and war hero. He fought bureaucracy tooth and nail to remain a pilot officer and was

ready for action when WWII broke out.

When his aircraft was shot down over Germany, Bader had to take off his artificial legs to parachute to safety. The Germans and British later co-operated to have a new pair of artificial limbs dropped into the prisoner-of-war camp.

Helen Keller had many disabilities. She became blind, deaf and mute at 19 months old. She overcame her disabilities to become an inspiration to people all over the world. With Anne Sullivan as her tutor this deaf, blind and mute girl went through private tuition and university, becoming familiar with learning techniques that disabled students take for granted today. Anne was allowed sit beside her, ask questions, and gets Helen's answers by means of 'touch' sign language.

Admiral Lord Nelson was a renowned naval icon and British hero. The loss of an eye and an arm in no way hindered him in his fighting prowess or his way with the women.

David Blunkett is a British politician who is blind. He was hung out to dry over some passport scandal to do with his lover's house cleaner. Not one effort was made by him or anyone else to use his blindness in order to get the sympathy vote.

These people took on the world on their own terms, asking no quarter and giving none. They all did things and accepted the consequences, good or bad, of their acts. The mantle of responsibility was sometimes heavy on their shoulders;



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sometimes their friends were few. Nevertheless, they measured up. They showed that they were made of the right stuff.

Prosperity has brought many new problems to Ireland, none more threatening to the nation's health than the growing incidence of obesity, particularly among children. Jennifer Banks reports.



The Hand That Lays the Table

Obesity is one of Ireland's fastest growing health problems. One in eight Irish people are obese and every second person is overweight.

The trends from the second SLÁN survey on people's lifestyles show that as a nation we are becoming progressively heavier – a fact underlined by the 30 per cent increase in reported obesity levels over the last four years.

Obesity is a complex condition that affects and threatens to overwhelm virtually all age and socio-economic groups. Its health consequences range from increased risk of premature death to serious chronic conditions that reduce the overall quality of life.

Obesity in children has been identified as an emerging public health problem, particularly in the western world. Data from recent surveys indicate that one in five Irish children is overweight and one in 20 is obese. Worryingly, the age of onset of obesity in children across the world is falling and a child is twice as likely to be an obese adult, if obese in childhood.

Addressing the trend and scale of overweight and obese children in Ireland is a priority. To do that we need to look at the eating and activity habits of children and what influences these. Less than half of teenagers aged 15-17 years take part in regular physical activity and the average schoolchild's diet has a higher than desirable fat content, a significant proportion of which comes from high fat, energy dense snacks.

* Rose is a mother of four children under ten, three of whom are overweight and the other who is diagnosed as obese. When asked why this situation has arisen she feels that it directly relates to the



advertising of high fat foods designed for children.

"Every time I go shopping I am under pressure to buy these foods. It's all well and good saying don't buy them but when you have four children ranting and raving it's easier to give in and have done with it." Rose accepts that she holds responsibility for the food her children eat, but feels that the Government should ban food advertising during the day and maybe then she can have a chance to put things right.

Does a parent have the right to blame advertising for what their children eat? After all, it is the parents who buy and serve the food. And should children be spending so much time watching TV in the first place? Valid questions with both parents and Government giving opposing answers.

The pester power of a child should not be underestimated and advertisers know this. Every Christmas parents are confronted with 'the must have toy', with most pushed to the point of delirium trying to get their hands on it. The same principle applies to food. If the advertisers tell children that mum is great only if she puts a certain product in your lunch box, what hope is there for parents.

Last summer the Green Party called for

all advertising aimed at children to be banned and demanded that the Government re-introduce the sports grant which provided schools with funding to provide equipment and coaching. Without this money schools would be unable to provide adequate physical activities for children, the lack of which is a major contributing factor in childhood obesity.

Rose is on a low income and is unable to pay for after school activities. "If you have the money then the kids can go swimming and play football two or three times a week. I can't afford this. We have no facilities for them to play outside. The local playground has become a haunt for junkies and the field where the boys used to play football has been built on so they spend their time watching TV or playing video games." It is a sad fact, but the building boom Ireland is enjoying has come at a price and open spaces where children could play are now fewer and disappearing by the day. Rose believes that as a first step to rectifying this, the Government should have a planning clause that allows for the provision of sport facilities with each new estate built.

On the issue of obesity, the Department of Health stresses that it can only provide information and cannot be responsible for what children eat. The National Taskforce on Obesity has prepared leaflets in conjunction with the Department which are available free from health visitors, libraries school and GPs.

So, in the absence of a ban on advertising, the clear message to parents is to stay strong or don't bring your children shopping. They might never thank you for it, but you'll be doing them a favour with lifelong consequences.

Mary Healy investigates the chronic shortage of rheumatology services in Ireland



The Worst In Europe

An estimated €6 billion per year in lost working days in Ireland is attributed to arthritis, according to Professor Barry Bresnihan, a consultant rheumatologist and chairman of Arthritis Ireland.

Professor Bresnihan was highlighting the need for the development of rheumatology services throughout the country. He said that 34% of women and 24% of men suffer from arthritis, or joint pain, and that the disease carries a significant burden of ill-health and disability. Stressing that a window of opportunity existed where early diagnosis and treatment could prevent disability, he said that inadequate services were resulting in critical delays in the diagnosis of common treatable diseases. "If services were developed people could remain at, or return to, work and retain their independence. This would also lead to a reduction in pressure on primary care, emergency and orthopaedic services," he said.

Consultant rheumatology services in Ireland are mainly based in the three major cities with medical schools i.e. Dublin, Cork and Galway. There are currently 23 approved permanent Consultant Rheumatologist posts in the public sector. The majority of these are based along the east coast while three are based in Cork. Waterford has three and Limerick, Manorhamilton and Galway, have one each.

However, Professor Bresnihan said that the western, north-eastern, mid-western and midlands regions are in urgent need of additional posts in order to provide a minimum service. Although ranked among Europe's top economies, Ireland lags behind its European counterparts in its ratio of rheumatologists per population. Ireland currently has one per 186,000 of population whereas the recommended number is one per 85,000. Some countries have a higher number. For example, Switzerland, with a population of 8 million, has 350 rheumatologists, while even poorer countries such as Croatia, has 4 times more than in this country. We are bottom of the league in Europe, according to Professor Oliver Fitzgerald of the Irish Society of Rheumatology and a board member of Arthritis Ireland. Professor Fitzgerald said that rheumatology services in Ireland were seriously understaffed. He stressed the



Anne Marie Healy: believes people in Mayo should lobby to have a rheumatology unit set up in the county.

importance of early medical intervention in order to suppress the disease. "Without it patients can and will be disabled," he said.

The longest waiting list for a first appointment with a rheumatologist is in the Health Service Executive's (HSE) Western Area, where over 800 patients are waiting to be seen by Dr Robert Coughlan, who is based in Merlin Park Regional Hospital, Galway. According to Dr Coughlan, some of these patients have been waiting since 1998/99 and include "up to 100 urgent cases who are in danger of permanent joint damage." Dr Coughlan was, until recently, the only consultant rheumatologist for the region.

"A minimum of four consultants are needed to provide a proper service, which would include more clinics, fewer patients per clinic and more patient contact," he said. He pointed out that most rheumatologists are also general physicians and are therefore unable to devote all of their time to rheumatology.

Some patients believe they are victims of inadequate rheumatology services, such as 35-year-old Anne Marie Healy from Belmullet in Co Mayo. Anne Marie was diagnosed with arthritis at 10 years of age. "I was in a lot of pain and my mother took me to the doctor who prescribed steroids and aspirin and said I would grow out of it, but I had no follow-up treatment."

Unfortunately, Anne Marie didn't grow out of it. Despite her tender years she has undergone numerous surgical procedures, including joint replacements in both of her hips, knees and shoulders. She has also had an elbow replacement. "If I had been able to access proper ongoing treatment in Mayo in the early stages of the disease I believe that I would not have had to endure so much pain and joint destruction," she said.

Anne Marie believes that people in Mayo should lobby to have a rheumatology unit set up in the county. "I live over 120 miles from Galway and it is a 3-4 hour drive, with another 3-4 hour wait in the clinic to be seen. People in pain should not be expected to do this," she said. However, despite her experiences Anne Marie maintains a positive outlook on life. She has done a number of courses over the years and is currently doing a Heritage Studies course at the Galway-Mayo Institute of Technology in Castlebar. "I don't dwell on the negative but keep occupied and set goals for myself. You have to get on with life," she said.

A campaign, launched by the Mayo branch of Arthritis Ireland, to have a rheumatology unit established at Mayo General Hospital, has been ongoing for the past 11 years. A spokesperson for the organisation said that "news of a second post for Galway is to be welcomed, but it will not alleviate the hardship of Mayo patients, who number over 14,500, many of whom have to endure a round trip of over 200 miles to Galway in order to access treatment."

The organisation is calling for the setting up of a unit in Mayo "as a matter of urgency", declaring that rheumatic disorders account for one third of all patients who are disabled. Measures must be implemented to ensure that people with arthritis are helped to lead a productive and healthy life as they age," the spokesperson said.

A statement from the HSE (Western Area) said it will continue to pursue the case for additional funding to provide three rheumatologists for the region. However, despite numerous requests the HSE was unable to provide a comment regarding the general shortages in rheumatology services throughout the country.

Declan Bohan has been severely ill with ME for almost half his life. But compounding his huge pain and suffering has been the struggle to have his illness, not just recognised, but even believed. Jacqueline Johnston-Fagan reports.



'They Made Me Feel Insane'

Can you imagine having an illness that is so physically and mentally debilitating that it has a catastrophic effect on your personal and social life and has diminished or completely removed your ability to earn a living, complete your education or carry out many of the ordinary functions that most people take for granted? Then add to that the crippling damage that is caused when you find that your illness is often disbelieved, minimised or cruelly ignored by a significant proportion of the medical profession and society generally.

This is a common experience for people with the illness Myalgic Encephalomyelitis (ME) – also known as Chronic Fatigue Syndrome (CFS). Classified as a disease of the nervous system by the World Health Organisation (WHO), it sadly remains one of the few illnesses that those with the condition struggle agonisingly to have diagnosed and treated. In addition to battling a debilitating illness, they often endure the equally painful experience of having to fight to be believed, accepted and understood.

Declan Bohan; a 32-year-old Dubliner, has been severely ill with ME for almost half his life. "I became exhausted after the smallest amount of exercise. I had constant pain and weakness in muscles and joints. I had difficulty sleeping and became so ill I had to leave school. I thought I'd be back in six months or so. The weakness is something that I never want to feel or even think about again. When I think about it, I want to throw up. To put this into perspective, at the moment, I am so weak and dizzy that I need a crutch to steady myself. I have to sit while chopping vegetables, but the original weakness was inhuman. I hadn't the strength to think for months."

Compounding Declan's pain and suffering was his increasing sense of isolation and alienation as he fought to have his illness recognised, accepted and worst of all, believed. "When I said I have no strength at all and I have pains all over and my lymph nodes are swollen, they (doctors) told me that I was perfectly healthy. They made me feel insane and ashamed of myself. What was I supposed to tell my friends? That I'm ill but the doctors don't believe me? And would I then have expected my parents and teenage friends to believe me over doctors? Feeling so desperately ill and then having no one to turn to just for belief and acceptance, makes it ten times worse."

Declan's sense of loss is palpable when he speaks about growing up with ME. "I honestly



Tom Kindlon.

feel like something took over a young man's body and ruined his life. I have lost all connection with who I was. Was that really me who was able to run and swim? Was that really me who had girlfriends and danced and used to make people laugh? Was I really that young boy who though he'd be someone someday?"

The sense of loss and isolation that Declan so candidly describes is common among people with ME. ME organisations believe that this can only be addressed when the medical profession and society in general, learns more about the illness and affords the same consideration and respect to those with ME/CFS as is rightly paid to people with other types of illnesses and disabilities.

As Declan so poignantly says, "I have never wanted sympathy in my life – ever! It's useless. All I have ever wanted was for people to understand how sick I am and to believe that I give 110 per cent every day. If I gave anything less over the years, I simply wouldn't be here. I have met quite a number of people with ME and every single one has been a fighter. Not only that, but they also seem to me to be the type of people who would never accept or want sympathy. Understanding and acknowledgement of how sick we are is enough."

It is estimated that there are approximately 10,000 people with ME in Ireland at present and their sense of isolation and despair is rarely reported. At present there is no definitive diagnostic test or cure for ME. Diagnosis is normally made when the following criteria have been fulfilled and other illnesses have been ruled out.

- Severe, debilitating and disabling fatigue present for more than six months usually made worse by physical exercise, and four or more of the following symptoms:
 - Impaired cognitive functions (inability to concentrate, calculation difficulties, memory disturbance, spatial disorientation, frequently saying the wrong word, being in a 'fog')
 - Chronic sore throat – often with recurrent flu-like illness
 - Tender and swollen lymph nodes – especially neck and underarms

- Muscle pain
- Multi-joint pain
- New headaches – often severe
- Non-refreshing sleep

Ireland's chief medical officer, Dr Jim Kiely said, "I recognise that ME/CFS is a source of significant morbidity in the community and that, when so little is known about the cause of the illness, there is serious concern about how the illness is diagnosed and those who suffer from it are treated. I agree that health care professionals of all types need to have a far greater awareness of and capacity to identify the illness, diagnose it and manage the illness and those who suffer from it."

Concerned ME groups around the country call for an immediate improvement in the diagnosis and treatment of ME so that Declan and all those with this incapacitating illness no longer experience the isolation and exclusion often felt. May 7th to 14th marks ME/CFS awareness week when organisations like The Irish ME/CFS Support Group hold huge publicity drives in an effort to offer information and raise awareness about the illness. Their Blue Ribbon Campaign will take place on International ME Day, May 12th.

The Irish ME Support Group's assistant chairperson, Tom Kindlon, is himself severely debilitated with the illness. He says that Declan's experiences are not uncommon. "Declan's story is not untypical of the stories we hear daily from people affected. The group concentrates a lot of its efforts on raising awareness as an early diagnosis greatly improves the prognosis; if more people could only be diagnosed earlier, much of the chronic disability people with ME have to endure would be reduced. We also try to raise as much money for research as we can, through fund-raising events such as the sale of blue ribbons. Research has progressed in recent years so that few who follow the research can doubt the existence of the condition. The next stage is to develop tests that can be used by doctors in their surgeries as well as building on existing research into the underlying causes of the condition, so that treatment for the condition will be less hit-or-miss than it is at the moment."

For further information, contact the Irish ME/CFS Support Group, PO Box 3075, Dublin 2. Telephone 01 235 0965 or email info@irish-mecfs.org

David Quinn **looks at some of the measures that are being put in place to build an intercultural Ireland.**



Uniting Ireland

Intrinsic attitudes towards immigrants into Ireland have changed dramatically since the days when race relations came no closer to our shores as a real issue than the battlegrounds of Toxteth and Tottenham.

But regardless of the rights or wrongs of our immigration policy, both sides of the argument are being increasingly dominated by stark images of what will become of Irish society if race relations break down. So beyond the rhetoric, exactly what is being done to build an intercultural Ireland?

'Know Racism' is a three-year programme, which aims to create the conditions for building an inclusive society in Ireland, where issues of racism are addressed and cultural diversity underpinned. The National Action Plan against Racism is a continuation of the Government's 'Know Racism' Awareness Campaign and was launched by An Taoiseach, Bertie Ahern, and Minister for Justice, Michael McDowell, in January. Under the plan, a grant scheme is provided to organisations contributing to a greater understanding of racism and cultural diversity.

Meanwhile, to mark the beginning of European Week Against Racism, which took place in March, the National Consultative Committee On Racism And Interculturalism, in partnership with the Equality Commission For Northern Ireland, launched an information handbook entitled 'Seeking Advice And Redress Against Racism In Ireland'.

The handbook is aimed at providing advice for a wide range of organisations and agencies, north and south, working with refugees, asylum seekers, members of the travelling community and the general public.

"There needs to be more co-operation



Style guru John Rocha: backing the Know Racism campaign.

in Ireland, north and south, to combat racism. The handbook provides essential information about where you should complain if you experience racism in either the Republic of Ireland and Northern Ireland," said director of the NCCRI, Philip Watt.

The NCCRI in conjunction with Poetry Ireland is also co-coordinating a Secondary Schools Poetry Competition for second-level schools nationwide. Spokesperson Jacqueline Healy said the response to the poetry competition was overwhelming and that the competition would be developed further in the year ahead.

In addition to these initiatives, changes

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in legislation have been an important element of the official response to the growing incidence of racism. The Aliens Act of 1935 remains one of the principal statutes in the area of immigration. However, new legislation is being brought in under the National Action Plan and will underpin the rights of victims to legal redress.

Additionally, it will be deemed an offence under new by-laws to make an offensive remark to an individual on a bus, train or DART. These bye-laws being brought in by CIE could possibly result in a conviction of a person prosecuted under incitement to hatred laws. This sets out a clear commitment from organisations operating within the public service to ensure that anti-racism measures are being upheld and seen to be enforced.

If you would like further information on the Government's Action Plan, hard copies are available from: The Department of Justice, Equality & Law Reform (Equal Status Division).

The information handbook 'Seeking Redress Against Racism In Ireland' is available from the National Consultative Committee on Racism and Interculturalism, Third Floor, Jervis House, Jervis Street, Dublin 1.

Domhnall Bruic **writes about his personal experiences of living rough on the streets of Galway**

Tonight, I am facing the ever-growing problem of homelessness. I smoke a hand-rolled cigarette and slug from a can of cheap cider in the "Spanish Arch" area of Galway city, opposite the large, many-roomed Jurys Hotel. I have a duffel bag containing all my worldly belongings and just enough money to keep me in strong cider and fags for the night. If I spare the money I should spend on food, I'll be able to buy some whiskey and then food will be whatever I might glean from outside Mc Donald's come the small hours. I'll find some cardboard at this time to sleep under and the Archway will be my roof for the night!

I'm painfully going through the experience of being homeless-skirting along the margins of society, also slowly beginning to realise the help available to me through various organisations in place in Galway city which try and address my plight. I'm 29 years of age and have been without a home for eight months. I occasionally stay at the Fairgreen homeless men's shelter, but I prefer to rough it so I'm free to drink alcohol. I'm not very social as a person, I find it hard to relate to people in general, even to the many people in similar circumstances to me.

Coming from a dysfunctional family – my mother died when I was eight and my father was an abusive alcoholic – I was raised mostly by my grandparents and various aunts and uncles. I left home when I was 16 and have been in and out of various institutions since. I have consumed alcohol from an early age and it's the only thing that makes me feel comfortable. I have been diagnosed with Bi-Polar Affective Disorder, Manic Depression by another name, and am prescribed a course of medication to combat this, but against doctor's orders I sometimes combine drink and street drugs with these medications for momentary lifts of mood. Luckily, I have done my Leaving Certificate and one day I intend to make use of this. I notice that a lot of people look at me and think I've given up, but I think I'm simply going through a bad patch which one day I'll forget as a bad memory! I've been in psychiatric hospitals many times, but I think I can manage my own health better

Down but not out



than anyone. I can still manage to claim unemployment assistance giving the homeless shelter as my address, but I really should be claiming disability allowance on account of my medical condition. This would mean I'd also be entitled to a free travel pass and would be preferentially placed were I to apply for housing with the corporation and the council.

I've learnt that this issue is not exclusive to Galway city or its environs, this issue is

endemic nationwide and does not only apply to Irish nationals. Focus Ireland, the organisation set up to deal with homelessness in Dublin, see all nationalities seeking assistance, desperate to make use of their services, along with the Eastern Health Board, in an attempt to secure housing in the capital city.

I face the weekly difficulty of getting just €130 while wanting to secure accommodation. I'll need to come up with usually

Sean Richardson **says it doesn't matter what labels society places on people with disabilities as long as we keep ignoring them.**

Sticks and Stones May Break My Bones

four weeks rent deposit and the first week's rent in advance. Even if I managed this, rent is on average €65 weekly and I'd be looking to claim rent allowance from the health board. The health board make a one-off payment of the deposit, but in my experience landlords aren't registered and don't wish to deal with tenants claiming rent allowance. I guess this has something to do with landlords wishing to evade taxation. Therefore, I remain homeless, paying a weekly amount to the homeless men's shelter, staying there on bad weather nights, using the facilities and eating there during the day, but with the weather improving with the arrival of summer, I'll invariably be spending most of my time on the streets and outside, frequently sleeping rough.

The Fairgreen homeless men's shelter encourages the men residing there to put away some money weekly with the aim of accumulating enough for a deposit. I hope to get accommodation in the private rented area if I can find a landlord who'll be satisfied to sign the rent allowance papers. I'm also looking into the possibility of getting a place in a Simon community house, there are a couple of houses dotted around Galway city which are well-managed and run by a highly organised set of dedicated staff committed to gradually removing the issue of homelessness from the streets. Simon Community of course are only as effective and strong as the degree of donations and funding they receive!

In the future, I plan to talk with a social worker I met in the Department of Psychiatry when last a patient there, and then get onto the housing lists run by the corporation and council. I'll be facing a 5 year wait, minimum, but I optimistically see that at least I'll be in with a chance of having my own home someday. Positively, I see then my Leaving Certificate will pay dividends when I eventually apply to university as a mature student. Until that point, I face a waiting game. Tonight, as I feel the long cold spring evening, there will at least be cider in my belly and cigarette smoke in my lungs, but I'll have to be wary of the possible dangers of being "at home" out in the city streets...

No matter what labels the socially aware use to make life more comfortable for everybody, there will always be some stropky sods who take a perverse pride in being called crips or spastics, raspberry ripples or some such epithet to make the politically correct squirm.

The real purpose of exploring and identifying problems is not, God forbid, to solve them, but to maintain our image as caring social beings. So we have to go through this rigmarole of finding some acceptable tag to stick on things; this gives the game away at once. They don't seem to have realised that ever since we evolved we have spent a lot of time trying to forget all the labels we have found for each other: The terms idiot, cretin, subnormal, slow learner etc, were all at one time or another accepted as medically correct. The words "spastic" and "retard" are still used by teenagers as a term of abuse to each other. Disabled people are also inclined to abuse each other using inappropriate language.

It happens. It happens because people are human. We have territory to guard and provided there are enough to maintain a hold of that territory and not let anyone else grab it, then our means of guarding it, however reprehensible, becomes the norm. It is a form of social climbing after all to look and sound as "normal" as the rest. However entertaining that scruffy, drunken unshaven foul-mouthed individual using the Zimmer frame to stand at the microphone and do his version of "I Did It My Way", he won't be looked upon as part of the group unless the entire audience is pissed. And everybody will be sobered up tomorrow (including him) anyway and someone might decide that

it was not wise to trust some important project to him or to the audience.

Society cannot afford to have any real individuals in its midst. A few can be trotted out, but cannot be trusted with the big decisions. That is for the 'suits'. In the beginning we were labelled in order to find out if we were any bloody use. If we were disabled as opposed to invalid or crippled then there was some reason to hope that we could do something useful in society.

This was also the view held by many disabled, but not all. 'Invalid' gave some a sense of being part of society's salvation as our prayers were often asked for. But that purpose was soon discarded by the disabled themselves because by then we had discovered, like the able-bodied, that there were so many and varied ways of sinning and so little time left.

I was quite flattered for a while to be called "handicapped" because I assumed that I was good enough to have a handicap placed upon me, like a good athlete. Becoming politically aware that it was the ignorance of society that was handicapping me and not my own disability was some revelation. The disabled citizen is just as awkward and bloody-minded as the able-bodied and it is perhaps unwise to expect a huge surge of concern as to how society will shape up from here on in.

If we are strong it will not matter what labels are placed upon us. We will, I hope, be too busy to care. If we become weak and lazy as some able-bodied then a social worker will have to find some more labels. If the good and sane continue to ignore labels then we are reasonably safe.