

**Forward**

**Midlothian**

**Disabled People**

[www.forwardmid.org.uk](http://www.forwardmid.org.uk)



**Equality - Diversity - Inclusion**

## **Midlothian Disabled People's Assembly Launches in Midlothian!**

Have you ever wondered how it would feel to be part of a group of people with collective goals? A group of disabled people with Power, Potential and Determination. What might a Midlothian Disabled People's Assembly look like? What might a collective gathering of Disabled activists achieve? Vibrant meetings with guest speakers who inspire and challenge us from Health and Social Care and local politicians? A place where you may feel heard and supported.

On 27th March around 70 people gathered in St Johns and Kings Park Church, Dalkeith, for the First meeting of Midlothian Disabled People's Assembly, (MIDPA). Disabled People, carers, Health and Social Care professionals, local councillors, local voluntary organisations, community councils all in attendance. The day was introduced by Jeff Adamson, Chair of Forward Mid and Lothian Centre for Inclusive Living, with other spoken contributions from Councillors Jim Muirhead and Margot Russell, a very moving personal contribution from Sheree Muir from Forward Mid and Catherine Acton from Local Area Co-ordination. All participants were then invited to take part in vibrant, energetic facilitated table conversations, where people were invited to talk about their personal experiences and express wishes on how to improve aspects of life and services for Disabled people in Midlothian. It was felt that there was a sharing of many useful pearls of wisdom and ideas. These conversations and rich content will appear in a report of the event, available from mid-April.

The gathering ended with the celebratory Launch of the Disabled Directory for Disabled People 2019, an invaluable guide to assist and signpost disabled people to useful, up to date local information and contacts, that may help people to live a full and equal life. People then talked and mingled over a networking lunch and a chance to browse our stallholder marketplace, including; Midlothian Local Area Co-ordination, MS Therapy Centre, LCIL, Midlothian Extra Care Housing/ housing occupational therapy, Volunteer Midlothian, Midlothian Access Panel, VOCAL Midlothian, Forward Mid, Parkinsons UK, MIDCARE, RNIB, Deaf Action, Police Scotland, Inclusion Scotland. Some comments from feedback evaluations;

*"Very useful event. Great to have the input of disabled people and thanks for the fab directory"*

*"Great opportunity and was very focussed and helpful"*

*"It was very good. Well-structured and organised. A good range of people individual & participating. Really enjoyed it. Thank you"*

*"Thank you Midlothian & Forward Mid. Ahead of the field – as usual!"*



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Watch this space for the next Midlothian Disabled People's Assembly in Autumn 2019. If you want to know more or be more connected to Forward Mid or MIDPA, or would like a copy of the Directory - GET IN TOUCH;

☎ 0131 663 9471/ ✉ info@mvacvs.org.uk

## Sheree's Journey

My name is Sheree and I am part of the Forward Mid team

I just wanted to share some of my journey with you and how I became part of the team

Just over two and a half years ago my life was very different from today's life. I had a very fast paced hectic job. I ran a few times a week and I very much lived life on the go! never stopping. I was independent, full of life remembered everything, I was the go-to girl.

Unfortunately, I ended up with a knee injury. I was back and forward to the hospital, they had a plan for me. I had to be signed off work I was in a lot of pain. within this period, I started with other symptoms and this led me to end up in A&E just after Christmas 2016.

From there everything thing changed. I was in a hospital for 8 weeks the Doctors doing every known test on me. I was then diagnosed with Complex Regional Pain Syndrome (CRPS) I was discharged

- sent home -get on with this new life. I ended up having to use a wheelchair, I lost my job, my independence and I had to ask everyone for help to even do the easiest tasks.

My life had done a 180 and I have become the opposite of what I ever was. It was now hospital appointments, feeling a prisoner in my own home. Isolated from the world and there very lonely. Along with living with this condition that causes many things to happen to my body, but chronic pain is just one of them.

While I continue to live this different life, I had an OT lady come visit me and assess my different needs within my home and discuss my isolation. She put me in touch with the LAC's (enable Scotland), Catherine & Sue came to visit with me. We chatted about various barriers and challenges I was facing. One is going out in my wheelchair and gaining confidence to speak to people whom I knew, but they did not know what had happened to me. I felt very embarrassed being in a wheelchair and people's reaction to seeing the 'new me' and what do I say to them when they ask? The other was going on the bus. From here Catherine and Sue visited regularly and we attempted to tackle each issue-: Next on the list-I was constantly wondering and saying - 'there has' to be other people out there that must be in a similar situation as me in Midlothian. Having the same issues of isolation, change in circumstance, wanting some human interaction?

LAC suggested I come to Café Connect - it was a meetup, just a coffee and a chat. This is what I was missing in my life! People to connect with and just a chat-there are only so many kisses & belly rubs from my silent companion Ted, my dog, that I can accept.

Café Connect day came I remember Catherine driving down, I was so nervous. this had been over a year since I had done anything out of my comfort zone. I had nothing to worry about, it was very



welcoming. Not one person asked what was wrong with me or gave me that sad look. I was just Sheree again - Just Sheree.

I was introduced to Eric who told me all about Forward Mid, what they do and the team of volunteers who meet up and would love to meet me. From that day I was very welcomed into the team, it was just what I was needing.

I have helped with the newsletters, given my opinion on issues and ideas that are relevant to Forward Mid and what they promote and work for. They have listened to me, I have laughed, cried and moaned and I am accepted. They came into my life just at the right time.

We meet for coffee and chat about anything or any plans about Forward mid and what we can do for the community. I get to use my brain again I have dates in my diary to meet up and meet the amazing group of people I have been lucky enough to have come into my life.

All I can do is say thank you to Sue and Catherine at LAC's thank you to Eric, Marlene, Jeff, Iain and Graham for making me feel human again, no pressure to do everything. We all have similar lifestyles in common. They understand if I am having a bad week and that is okay. I have a purpose to keep going on with this journey I am on. Along with this horrible medical condition I live with daily, I get glimmers of being Sheree, sharing thoughts and ideas and doing actual tasks I have said I can do and being part of a team.

So, ending this - there are groups, charities and coffee mornings out there, we just need to share with our Midlothian Community and suggest to anyone that is struggling or just looking for that social interaction and share the knowledge. Offer telephone numbers or information. It's the first step for someone but it could open a whole new world for them.

**Thank you for reading Sheree.**

## Changes to Midcare Alarm Service

Following a review of charges for the Midcare Alarm Service, it was approved that from the 1st of April 2019 the cost will increase from £3.15 per week to £3.85 per week. This is a rise of 22.24%. To be paid quarterly at £50.05.

Midlothian Council claim that they charge considerably less than many other local authorities. That will mean absolutely nothing if you have to live on benefits.

If you have a Midcare Alarm Service user and pay by Standing Order, Midlothian council ask you please to increase the amount you pay with your bank.

### The Midcare Alarm Service

Through the use of technology the Midcare alarm service enables you to continue to live independently in your own home for as long as possible, allowing you to feel safe, secure and supported.

The East Lothian control room receives the initial alerts from the equipment and passes this on to ensure that an appropriate response is provided. The control room is staffed 24 hours a day, 365 days per year.



### What responses are provided?

Response can be provided by:

- ▶ A key holder such as family/friend/neighbour, who may be requested to assist in an emergency (service users would provide details of these contacts).
- ▶ A Midlothian based responder service provides a back-up when required.
- ▶ If appropriate, a client's GP or the emergency services will be contacted.

# Dobbies Melville – a new look and a new approach



Dobbies Garden Centre in Melville is located in Lasswade just off the A772 Gilmerton Road near the Edinburgh City Bypass. It is the largest garden centre in Scotland and has recently gone through a major refurbishment project. Forward Mid started working with Dobbies in August 2018, following the group reaching out to the company and a positive relationship has evolved to ensure accessibility, signage and parking use is being considered as part of the works to the store.

Ross Anderson, Head of Central Operations and Health & Safety said: "We are very grateful for Forward Mid coming directly to us with their suggestions. Since developing a productive partnership with the group we have implemented a number of their recommendations, such as a new blue badge parking layout incorporating a new drop off point for larger vehicles and those requiring tail-lift access. We will continue to involve Forward Mid in any future developments at our flagship store."



In the car park, there are plans to drop kerbs, install additional signage and new crossing points to the front door area. Additional double yellow lines have already been implemented in key access locations and there are new barriers along the side of the path at the play park to stop cars blocking the pedestrian route at this section.



Inside the store, the layout has been designed with wide aisles and a brand new 'Changing Places' toilet.

Dobbies looks forward to continuing a collaborative

relationship with Forward Mid and that the experience of visiting Dobbies has been enhanced for all customers as a result of these new positive steps.



## Graham's Story

7 years ago I ran the Edinburgh Half Marathon, the year before that I ran a 10K and regular 5k Park runs, I was fit and healthy and had worked in Financial Services for almost 30 years.

The following few years brought a gradual change in my fitness level, no longer could I run as far, the Gym sessions were becoming few and far between,

I noticed aches and pains I had never been aware of before, I had trouble turning over in bed, I was having balance issues, I pretty much stopped running

### **And I noticed I was doing less but getting more and more tired and fatigued,**

I wasn't unduly worried until the Christmas of 2015 when my wife and I both noticed my left hand shaking, this was worse when I became stressed or agitated, it happened mostly at rest sitting watching TV for example, Visits followed to my GP and Neurologists ( I was fortunate my GP had a good Knowledge of what might be wrong).

I was diagnosed the spring of that year with Parkinson's Disease, in some ways it was a relief to my family and myself to eventually know exactly what was wrong, although it was still a very upsetting life-changing time,

I had no idea at the time how much I would come to value health professionals like Occupational Therapists. Speech Therapists. Parkinson and Stroke nurses Physiotherapists, and also carer organisations like Vocal Midlothian, who were a great source of information and comfort to my wife Denise.

The information I was given by my Neurologist was excellent but I did what most people would probably do, I searched Google and watched nothing but YouTube Videos on Parkinson's ( not a good idea) so much misinformation was on the internet I went on the Parkinson's UK website, that day changed my life, My wife and I have since been to 3 Parkinson's UK conferences in Stirling, meeting and helping other people with the same diagnosis.

I have also been Volunteer Educator with Parkinson's UK for 2 years now, I go into care homes and we provide a free service to support staff doing 1 hour long seminars on explaining how the disease is different for every person, how important timing of medication is, and the amazing work Parkinson's UK does as the leading Parkinson's Charity in the UK, raising awareness and helping to raise vital funds for research to help hopefully one day find a cure for this horrible disease, At this moment in time we do not have a cure for Parkinson's Disease, it is a progressive Neurological condition which kills off the cells in the part of the brain called the substantia nigra, that leads to a reduction in a chemical called Dopamine to the brain, which affects both motor and non- motor skills, Parkinson's UK vision is to find a cure and improve life for everyone affected by Parkinson's Disease, we influence and fund groundbreaking research to advance understanding and improve treatment.

We also provide support for families and carers both practically and emotionally,

If you would like more information about Seminars please contact me on [Grahamthomson1205@outlook.com](mailto:Grahamthomson1205@outlook.com) or 07775785786

Or the Charity direct. Scotland Office [scotland@parkinsons.org.uk](mailto:scotland@parkinsons.org.uk)

Telephone 0344 225 3724

Thank you for reading my Story

I would like to thank Forward Midlothian Disabled People. (Forward Mid ) for asking me to write this and allowing me to attend meetings and be involved.

Eric Johnstone. Jeff Adamson. Ian Tait. Marlene Gill. Sheree Muir.

**Graham Thomson**





**The Scotland Against the Care Tax campaign group warned that THOUSANDS of disabled people who receive personal care are set to be disappointed when the Scottish Government's policy for free personal care for people under 65 comes into effect on 1 April 2019.**

This policy is aimed at bringing people aged under 65 who have been assessed as needing personal care into line with people over 65 who have received free personal care since 2002.

Government ministers had said that 9,000 people would benefit but Scotland Against the Care Tax (SACT) a national group of disabled people's organisations who are campaigning for all care charges, personal and social, to be abolished dispute this. Following a Freedom of Information survey of Scottish Councils, they calculated that the true figure will be one-third lower – 6,000.

SACT say Meanwhile those with savings of over £27,000 will benefit most, the campaign says. This is because those already paying the full cost of their care will pay less when personal care is free, whereas people who pay only what they can afford may find they still have to pay the same sum towards non-personal care. SACT, which is calling for all care to be made free to those who need it, claims this is unfair.

Ian Hood, a researcher for SACT, said, "The Scottish Government has over-promised the benefits of its new policy. Most people who have social care needs in Scotland will have no change in their care charges. They will come to feel taken advantage of by 'clever politicians' and their civil servants who have followed the letter of the law but not its spirit."

Jeff Adamson, SACT chairman, added: "Councils have already been paid £30 million to implement the policy. But disabled people are still having to wait for who knows how long for information on how the policy will be applied and how it will affect them."

SACT's FOI requests also revealed that many councils are still not ready for this policy change. It showed 19 out of Scotland's 32 councils couldn't say which clients received only personal care or both personal care along with other forms of social care.

A Scottish Government feasibility study suggested most people receiving care services receive around three hours of non-personal care for every hour of personal care but councils responding to SACT said that the split for their clients was much more evenly split.

Ian Hood added: "The policy is based on flawed assumptions and is actually likely to cost less than they have put aside because of this. But that also means far fewer people will benefit than expected." Some councils are likely to face legal challenges over the way their care has been assessed, he said.

A Scottish Government spokesman said: "The extension of free personal care to people under 65 will be fully implemented by April 1."

"The budget includes £30 million this year to cover this extension so free personal care will be available to everyone who is assessed as requiring it, regardless of their age, condition or income."

It should be noted that in 2017 when this policy was first announced the budget for its implementation was £11 million. SACT are at a loss to explain the £19 million increase in costs and, as yet, haven't received any explanation from government officials.

You can read more about social care charging and the Scotland Against the Care Tax campaign by visiting their website at: [www.scotlandagainstthecaretax.co.uk](http://www.scotlandagainstthecaretax.co.uk) or on Facebook at: [www.facebook.com/ScotlandAgainstCareTax](https://www.facebook.com/ScotlandAgainstCareTax)

# One Big Day - Edinburgh

21<sup>st</sup> September 2019, Royal Highland Centre, Ingliston, Edinburgh One Big Day - Edinburgh

## Event description

One Big Day at the Royal Highland Centre provides the perfect opportunity to discover everything you need to know about worry-free motoring with the Motability Scheme. There is a huge range of cars, adaptations, Wheelchair Accessible Vehicles, scooters and powered wheelchairs on display and what's more, admission is free!

## Event hosted by

One Big Day Edinburgh is an official Motability Scheme hosted event.

## Opening days and times

Saturday 21 September 2019

09:00 Hrs - 16:00 Hrs

Event location

Royal Highland Centre

Ingliston

Edinburgh

EH28 8NB



## Getting to the Royal Highland Centre

### By car

The Royal Highland Centre sits off Glasgow Road (A8) between Newbridge roundabout and the A8/Airport roundabout, one of the main routes into the city.

Access to the Royal Highland Centre is from A8/Airport roundabout on to Eastfield Road. From there, signposts provide directions to the venue along Fairview Road onto Ingliston Road.

### By bus

From Edinburgh, Lothian Buses run regular services including the 35 and the Airport Express (100), we would recommend using the Airport Express as this will drop you in the most convenient location to access the Royal Highland Centre.

### By rail

Haymarket is the nearest train station with excellent train links across the UK. Lothian buses run regular services stopping outside Haymarket Station and dropping off adjacent to the Centre. Call Lothian Buses ☎ : 0131 555 6363 for more information.

Taxis are plentiful outside Haymarket station and there is a transfer time of around 15/20 minutes to the Royal Highland Centre.

### By public transport

Contact Traveline on ☎ : 0871 200 2233

For more information contact [www.motability.co.uk/](http://www.motability.co.uk/)

## Virus alert in PDF Creator

In January 2019 PDF Creator ran an update program, this program update allowed a Virus to be downloaded with it. Any company that downloaded this uses PDF Creator, is now spreading a bloating virus that duplicates all the files on your computer every time you switch it on.

This means one file, that is 10 kb to double at every time you start, second day 20 kb third day 40kb third day 80 kb fourth day 160 kb fifth day 320 kb 10 day 9996 kb so it quickly bloats your hard drive so it does not work.

Before you open or download a PDF File right click on it and run your Anti-Virus as administrator. Especially if it comes from a big business that has no control over there software and have to use what is available.

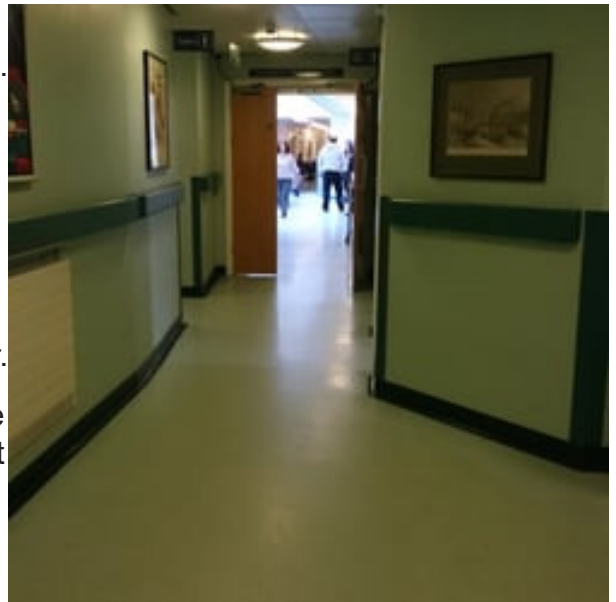
Be careful

## A letter to attend the Leith Community Treatment Centre

I am a wheelchair user, and my gender is male. This is not a barrier-free environment so when I was told I would need to return in the future, I informed the doctor that certain things would need to change first.

My first change would be to provide a male disabled toilet that is big enough to accommodate a wheelchair with room to transfer, not one disabled toilet tucked into a inaccessible section of the female toilet that is too small to accommodate a wheelchair and transfer to the toilet, or to place one disabled toilet outside the female toilet that is big enough for a wheelchair user to transfer.

As space is a premium in this building, the elevators are extremely tight with one set of controls, the appointment was on the first floor. When I entered the elevator the controls were behind me out of my reach, the elevator is not big enough for a wheelchair and carer. I was at the mercy of whoever pressed the button and when I reached a floor I had to ask where I am.





Exiting the elevator there is a long narrow corridor with a three-quarter door and side panel with top and bottom bolts. It opens out after that.

If you are a wheelchair user you may wish to phone in advance and express concerns about accessibility.

### Alternative Publications

Please like us on Facebook [www.facebook.com/forwardmid/](http://www.facebook.com/forwardmid/) 

Forward Mid newsletters are available in large print on request from Eric Johnstone ☎ : 0131-663-9471 or email [eric.johnstone@mvacvs.org.uk](mailto:eric.johnstone@mvacvs.org.uk) write to him at MVA, 4-6 White Hart Street, Dalkeith, EH22 1AE with your request. Electronic copies can be found on [www.forwardmid.org.uk](http://www.forwardmid.org.uk). The latest Firefox browser has the reader symbol  in the address bar, click and select narrate from left menu. The latest Safari Browser has the reader symbol  but does not read aloud. These only work on websites without errors. If you require help please contact Forward Mid and we will arrange to help you.

Edited by Iain Tait for Forward Mid