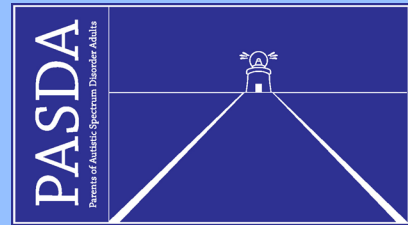


# PASDA NEWS

March 2013 ISSUE #31

Supporting families of adults with autism  
in Edinburgh & Lothian



## Independent Living Skills Profile

*Making it easier to tell professionals where you are, and where you want to go*

Scottish  
autism

Alongside Scottish Autism, we have developed something called an Independent Living Skills Profile Tool, to help you collect all relevant information about your family member in one place.

The purpose of the Profile is to gather information about an individual's present independent living skills from two perspectives: parent/carers and that of the individual themselves. This information can then be used to help fill out forms (such as benefits applications, Carer Assessments), speak to professionals and support staff, and to plan for the future.

The focus throughout will be what the individual can do independently, and what they can do with some support, as well as addressing things that they find difficult. The Independent Living Skills Profile should provide a baseline which parents and others could use to develop new support plans. It may also provide a bank of information for parents to use with others, such as doctors, social workers, support staff, teaching staff and community nurses (with the permission of the individual, where appropriate).

PASDA are offering **four** families the chance to be supported to complete the Profile between **March and June 2013**. This will involve meeting with Karina for up to three two hour sessions (either at 24 Hill Street or in the family home) to complete the Profile. It may be that you just require some preliminary instruction and then you can complete the bulk of the document in your own time. After the initial piloting of this tool, we will review it's effectiveness and then look at supporting further families to use the tool later in the year. If you would like to take up this opportunity, please contact Karina by **Friday 15<sup>th</sup> March**.

## Thistle Foundation & NHS —Lifestyle Management Courses in Midlothian

This Lifestyle Management Programme is designed to support adults who are dealing with difficult life situations, or who are living with long term health conditions and want to increase their ability to live as full a life as possible.



The programme helps people gain control over their situation by making use of and building on their own coping and recovery strategies. The course aims to boost confidence and self-esteem by acknowledging and celebrating the small successes participants achieve along the way.

The 10-week programme consists of group sessions lasting three hours. These sessions involve discussion, safe and appropriate exercise, and therapeutic relaxation. The course will take place locally.

For more information please call 0131 537 9883 or email [Alyson.Henderson@nhslothian.scot.nhs.uk](mailto:Alyson.Henderson@nhslothian.scot.nhs.uk) or [lyn.dewar@nhslothian.scot.nhs.uk](mailto:lyn.dewar@nhslothian.scot.nhs.uk)

## Impacting Services in Edinburgh and the Lothians

Your opinion can contribute to the evidence required to improve services, so if you do have time, please have your say here: <https://www.surveymonkey.com/s/AutismMappingParentsCarers>

If you would like a hard copy of the questionnaire, please let us know and we can post one to you.

Parents of Autistic Spectrum Disorder Adults (PASDA)

24 Hill Street, Edinburgh EH2 3JZ

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

0131 220 1075

[info@pasda.org.uk](mailto:info@pasda.org.uk)

Scottish Charity No. 042678

# REGULAR PASDA MEETINGS

## PASDA Information Meeting

We hold our main carers' meeting on the **second Wednesday** of the month at Autism Initiatives' One Stop Shop (24 Hill Street, Edinburgh EH2 3JZ). This meeting is open to all parents and carers of adults (over 16's) with an autism spectrum condition, living in Edinburgh or the Lothian's.

Next meeting: **Wednesday 13th March, 7-9pm**: This month, we will be having two short presentations. One is about *Care 4 Carers* and their weekends away. The other about the Alexander Technique, which is a form of movement therapy which many people on the spectrum find helpful.



**Carer Discussion Group** Our next carer discussion group is planned for **Friday 8th March 10am-12noon**, at 24 Hill Street, Edinburgh, EH2 3JZ. This is a small, closed meeting which provides an opportunity to raise issues which are current for you, and to share information and encouragement with other carers. Please let us know if you plan to come along. This group is facilitated by our volunteer, Hester.

## East Lothian Carers Group

This monthly group is open to parents and carers in East Lothian and takes place at *Carers of East Lothian* at 94 Musselburgh High Street. The group will meet next on **Thursday 28th March**, from 6.30-8.30pm.

## Partner & Spouses Group

Sessions will be as follows:

- Thursday 7th March, 2013 6-8pm Understanding your own physical and emotional needs
- Thursday 11th April, 2013 6-8pm Relaxation - why we must have it.
- Thursday 2nd May, 2013 6-8pm Caring - what else is there?
- Thursday 6th June, 2013 6-8pm Practical hands-on therapy

Please contact Karina if you are interested in attending. [karina.williams@aiscotland.org.uk](mailto:karina.williams@aiscotland.org.uk)

## West Lothian Carers Group—New!

The first meeting of our new West Lothian group will be **Monday 18th March**, from **6-7.30pm**, at Almond House, Quarryrood Court, Livingston, EH54 6AX. If you are interested in attending but this time does not suit you, please get in touch to let us know, as it may be possible to have some meetings at a different time. The first 6 months of meetings will be facilitated by PASDA staff, after which point we intend the group to be self-supporting. If you would like to volunteer to help facilitate, we would be glad to hear from you.

## Autism & Complex Needs Group

This group is for parents and carers of adults who have autism plus severe or profound **learning disabilities**. The next meeting will be **Monday 18th March**, from **11am-12.30** at 24 Hill Street. Please speak to Katie or Karina for more information and to confirm your attendance.



## Dinner and Cinema Trip—March Social Group

This month the social group will be going to Nando's for a meal and then to the cinema for a film. We will decide on the movie the week before, so if you have any suggestions, you can let us know when you reserve a place. We will be meeting outside Nando's at Fountain Park, on Dundee St in Edinburgh, at **6.30pm**, on **Tuesday 19th March**. Using our Creative Breaks funding, we can pay £10 towards your meal and cover the cost of your cinema ticket. The group will be led by Lucy, a member of the PASDA Committee. For more info or to book a place, please contact Karina by **12th March**.

**CREATIVE  
breaks**

# CARER INFORMATION & OPPORTUNITIES

## Free Legal and Financial Advice

VOCAL offer a number of free advice surgeries for carers who are looking for information on legal and financial matters from an expert in the field. All surgeries run regularly as below:

- The legal surgery is the last Friday of the month.
- The Long term care financial planning surgery is the 2<sup>nd</sup> Friday of the month.
- The POA surgeries are the 1<sup>st</sup> and third Fridays of the month.
- Benefits surgeries take place on a weekly basis and rotate through the days of the week in increase accessibility.

For more information and appointments, contact Jane on [JGreenacre@vocal.org.uk](mailto:JGreenacre@vocal.org.uk) or call 0131 622 6666



## Training to be a Volunteer Advocate

Heather is the parent of two adult sons who both have autism spectrum conditions. In the last year, she has begun training as a volunteer advocate as part of PASDA's partnership project with VOCAL. Here she talks a little about her experiences:

"To be a carer brings challenges that you can't plan for, or imagine what it might be like, until you experience it in some way. To be an advocate for a carer who is in need of that extra bit of support and at a



bit of a loss about where to go to for some much needed support, brings with it great satisfaction, and what you have experienced yourself, goes such a long way in being able to identify with the carer and their needs.

"Advocacy for carers is challenging, and you have to build up and find a strength you might not otherwise recognise in yourself. It's also hard when you are dealing with the professionals representing all sorts of services like education, social work or the NHS at times, but once this hurdle is overcome, it's good to feel on an equal footing and to feel that your input and support for the carer is as valid as the other professionals around the table who are making the decisions.

"Advocacy for carers is rewarding, and with a bit of a tough exterior, all of us can be effective in that role. It's worth exploring for those with a few hours to spare, with a commitment to the role and with some amount of flexibility to you can support carers at short notice. You meet some great people along the way!"

For more information on using the advocacy service at VOCAL or training to become an advocate, please speak to Karina at PASDA or Mark Johnston at VOCAL ([advocacy@vocal.org.uk](mailto:advocacy@vocal.org.uk) or call 0131 622 6666) .

## Sibling Support

Siblings of adults with autism often face difficulties. Many are willing to take on support roles, but they find it difficult to access the information needed to help their brothers and sisters with autism. They also need support for themselves and their own families. **The Autism in Maturity project** has joined forces with **Sibs**, the UK charity representing the needs of siblings of disabled people, to provide a forum for the siblings of adults with autism. This is a place where siblings can discuss issues and help each other.

To join the Sibs Forum, go to [www.sibs.org.uk/](http://www.sibs.org.uk/) and log in. For more information about *Autism in Maturity*, visit The National Autistic Society's website at [www.autism.org.uk/maturity](http://www.autism.org.uk/maturity)

## Our Peer Support Network: PASDA CONNECT

For many parents and carers it makes all the difference to have someone to talk to who really knows how you feel and who understands what you are going through. This is why we set up our peer support network, PASDA Connect, to link up people with similar experiences so that they can support each other when things are difficult and celebrate their successes together. We are always look for new carers to join the network so please complete and return a profile form if you haven't already done so.



## March 2013—Quick Guide to What's On at PASDA

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
				1	2	3
4	5	6	7 Partners Group 24 Hill Street EH2 3JZ 6-8pm	8 Discussion Group 24 Hill Street EH2 3JZ 10am-12noon	9	10
11	12	13 Carer Information Meeting 24 Hill Street EH2 3JZ 7-9pm	14	15	16	17
18 Complex Needs Group—24 Hill Street 11-12.30pm	19 Social Group— Nando's and Cinema Fountainpark, Dundee Street, Edinburgh 6.30pm	20	21	22	23	24
West Lothian Group Almond House, Livingston—6-7.30pm						
25	26	27	28 East Lothian Group, COEL, Musselburgh 6.30-8.30pm	29	30	31

### Parents of Autistic Spectrum Disorder Adults (PASDA)

Contact Details: PASDA, c/o Autism Initiatives, 24 Hill Street, Edinburgh EH2 3JZ

0131 220 1075

karina.williams@aiscotland.org.uk/katie.goudie@aiscotland.org.uk

www.pasda.org.uk

Contact Hours: Monday-Friday, 9-5pm

Scottish Charity No.: SC042678