

Diane Gooch - Chair of WSUN

Welcome to the first Newsletter for 2014 and my second as Chair of WSUN. As I start to put pen to paper I can hear the rain once again and my thoughts are with those in Wiltshire and the rest of the country who have been so badly affected by the floods. I hope when you receive this that the awful weather is behind us and we can look forward to the Spring and some sunshine. These past few months have been very busy for us all on the Management Committee as we settle into our roles and go out



and about to meet as many people as possible. A period made easier by the support given to us by all the Staff at WSUN. I know this year is going to be, as always, very challenging with more changes to the way services may be delivered. However, if we continue to work together, I am sure we can help to minimise the effect on service users and ensure the services continue to be responsive to all users needs. As always we value your thoughts on issues important to you, so please, continue to be in touch with your views or reactions to our activities.

Best Wishes

Diane Gooch

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Louise Rendle - Head of Network Services

2014 has proved to be busy so far; two well attended service user forums with speakers from Healthwatch and the Clinical Commissioning Groups. A consultation with Healthwatch England and our regular Safeguarding and Our Time to Talk group meetings. There has been lots of Outreach to your local communities and that's just in the first few months.

We are always looking for new opportunities to meet with service users and other organisations so that we can share information and your views. If you belong to a group or an organisation and you would like us to visit, please get in touch.

With 34 new members joining us since January, our membership continues to grow. Richard Conlon one of our new Outreach workers has been tasked with finding new and very different ways to engage with service users. I can't wait to see how this will develop. If you have any ideas, we'd love to hear from you.



Development Outreach Wiltshire

Another Memory Club Gets Under Way

Building on the success of the 3M's memory club in Royal Wootton Bassett, which has been successfully operating for the last eighteen months, and the Melksham Memory Club which started last October, WSUN is very pleased to announce a new memory club for Calne.

The Calne Memory Group held its first meeting on February 13th at Marden House. The first meeting got off to a great start with five people who either have a memory loss or care for someone with memory loss turning up to find out what the club was all about. Group organisers, Jan Bird, Gill Kosmyryk and Olga Tuffery were well prepared with archive material from Calne Heritage Centre, tea coffee and cakes and a selection of raffle prizes. WSUN staff attended the meeting to support the group.

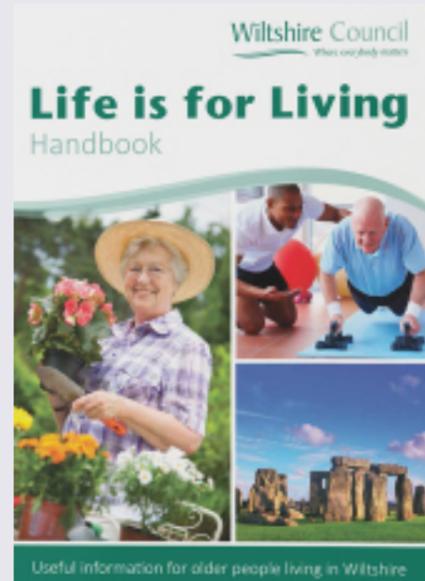
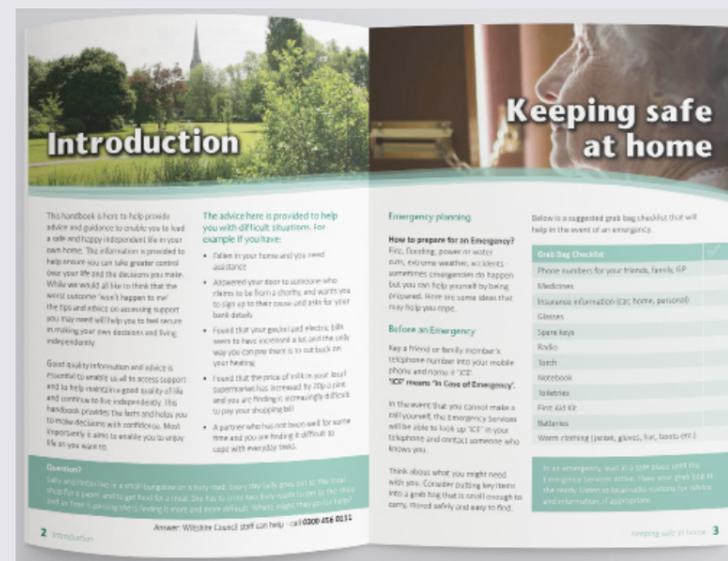
Calne Memory Group will meet fortnightly at Marden House on a Thursday from 10.00 – 12.00. If you live in Calne or the surrounding area, have a memory loss or care for someone with memory loss then you would be more than welcome to come along to a session, enjoy conversation and become involved in the events that will take place.

Life is for Living Handbook



Wiltshire Council has produced a new booklet full of useful information for older people. The booklet has information on keeping safe at home, including security and fire safety. There are also sections on benefits and money worries, advice for carers and keeping warm and staying well.

To request a copy email customerservices@wiltshire.gov.uk or call 0300 456 100.



©Elyssa Locker



The memory club at Wootton Bassett meets every fortnight on a Friday morning.

Memory Groups

Do you or someone you know or care for suffer from memory loss. Come and join one of our groups for a social gathering. All welcome.

The Riverside Club, Melksham meet 10.00am-12.00pm on the first and third Wednesday.

Marden House, Calne - 10.00am-12.00pm on alternate Thursday's.

The Civic Centre, Royal Wootton Bassett - 10.00am-12.00pm on alternate Friday's.

Please contact us on 01380 871800 for more information and the date of the next meeting.



Dementia Strategy Consultation

The draft dementia strategy was agreed by Wiltshire Council Cabinet and the Governing Body of NHS Wiltshire Clinical Commissioning Group in January and these organisations are now inviting people with an interest in dementia, whether through personal or professional experience, to contribute their comments and viewpoints.

The strategy outlines plans for how organisations in Wiltshire will work together to support people with dementia and their carers and families to live well in Wiltshire. With the number of people with dementia predicted to rise by 28% in 2020 to 8,350 people, the key message of the strategy is that dementia is everyone's business and we all need to play our part in making Wiltshire a good place to live with dementia.

To make this happen, one of the priorities within the strategy is to develop dementia friendly communities in Wiltshire. These will involve bringing together partners within local communities, including people with dementia, to deliver small improvements that make a difference to the quality of life for people living with dementia.

The strategy also outlines the care and support services that are available for people from the point at which they start to have concerns about their memory through to the end of their lives

The consultation is running from 20 February to 19 May 2014.

The consultation documents are available from the Wiltshire Council website where you can complete the survey online.

www.wiltshire.gov.uk/council/consultations/consultationwiltsdementiastrategy.htm

You can also request copies of the survey and consultation documents by writing to Rhian Bennett, Adult Care Commissioning, Wiltshire Council, Monkton Park, Chippenham, SN15 1ER or by telephone on 01225 712554 or by emailing dementiaconsultation@wiltshire.gov.uk. If you would like any help completing the survey do please contact us here at WSUN where we can arrange help with online and paper surveys.

Help to Live at Home

WSUN remains an important part of Wiltshire Council's 'Help to Live at Home' service (H2LAH). Our main task is to co-ordinate the Customer Reference Group (CRG), the independent group of volunteers who monitor the six H2LAH providers. This happens on a regular basis with teams of volunteers going to a provider, to contact customers, to find out how their care package, equipment and response service is progressing. The CRG reports back to WSUN who then put together a report for Wiltshire Council.

The CRG is shortly to undertake some new tasks as part of the H2LAH work. A group of members will become involved in evaluating the assessment and support planning for customers. This will involve looking at the initial assessments carried out by Wiltshire Council staff. We will see if these assessments meet the person centred approach that H2LAH asks for and compare the assessments to the support plans drawn up by the providers. The main purpose behind H2LAH is to enable people to stay in their own homes with the right support to help them live as independent a life as is possible and to help them to do the things that are important and meaningful to them. The assessments and support plans should reflect this.

In March members of the CRG were involved in Wiltshire Council's Peer Review. This is where officers from another local authority look at the way Wiltshire Council is doing things and seeing if they are achieving what they have said they wanted to achieve. H2LAH was part of the Peer Review and the CRG were spoken to by the Peer Reviewers.

One of the four Care Providers in the H2LAH service has approached the CRG to ask if it could undertake monitoring of its complex cases. These are customers who have very considerable needs and require much greater inputs from the Care Provider. This will be a very different kind of monitoring with CRG members going into the customers home to speak with them and their family on a regular basis.

Finally the CRG is going to be involved in the evaluation of a demonstration H2LAH project that is being put together by the Mears Group, one of the four care providers. This demonstration will be to show that the H2LAH project, in its truest sense, can work and improve the lives of customers. Methods of how the evaluation is to be carried out is currently being worked on by an associate member of WSUN's management committee with WSUN staff members and Mears group staff and consultants.

All this work means that the CRG needs to grow its membership to comfortably carry out all the tasks properly.

Younger People with Dementia



We are thinking of starting a group for younger people with dementia in Wiltshire. The group may be social, informative, activities-based - or a mix of all three.

As a first step we would like to gather information on the numbers of people who might benefit from such a group.

If you, or the person you care for, was given a diagnosis of dementia before their 65th birthday, please could you let us know. We can then invite you to take part in planning the group and exploring the opportunities that may be available. Please note you do not need to be under 65 now!

If you are interested in being involved please give us a call on 01380 871800 or email us info.wsun@btconnect.com



Customer Reference Group

WSUN are actively looking for new volunteers for the Customer Reference Group. We have a lot more work planned for the year ahead and we would like to increase the size of the group to help with the work load.

Advertisements have been placed through Develop on the Do-It website along with mentions on their Facebook and Twitter pages. This advert only recently went on and we have already had two enquiries with one person definitely interested in joining the group.

We have been looking at getting adverts placed on other volunteering websites, including targeting many different retired professionals groups, such as retired civil servants, service personnel and people with a background in social care, to name just a few.

The Customer Reference Group recently had a mention on BBC Wiltshire Radio morning programme promoting the fact that we would like volunteers. We are also looking into having a programme produced by Devizes Television, promoting the Customer Reference Group.

If you have any ideas of groups or organisations that may be able to help with expanding the Customer Reference Group please let us know. We'd also like to hear from you if you are interested in volunteering. Please contact Neil Bartram or Nick Crane at WSUN.

The Amesbury Mental Health Group

Ruth Underwood a very busy WSUN Member set up the Amesbury Mental Health Support Group with the help of Julie Edwards and Friends in February 2013. As you will see from the photo the group have just celebrated its first Birthday.

The group meets every Thursday afternoon at 2pm in Amesbury's visitor centre. Everybody is welcome whether or not you have experienced mental health problems. The group have a resource of literature on a wide range of mental health topics, free helpful materials and contact details of support services to share. Guest speakers have included Healthwatch the Avon and Wiltshire Partnership and local Councillors



The group enjoys arts and crafts , tea, cakes and chats and support each other. Members of the group attended the review of the Mental Health Strategy and are attending WSUN's forum with the Clinical Commissioning Group representatives .

The group will be key to our World Mental Health Day planning. Please see our website for planned events throughout the year. Well done all and thank you for your time, commitment and everlasting support to ensuring mental health is given high priority, recovery is helped and isolation reduced.

South West Learning Disability Network

The South West Learning Disability Network previously called the LDDG, has been in existence for over ten years - and provides a very valuable opportunity for anyone in South Wiltshire who is interested in and involved with Learning Disability, to meet up quarterly in the Salisbury Methodist Church Rooms, in St Edmund Church Street.

Everyone is welcome - whether Service User, Service Provider, Parent, Carer or related Voluntary Organisation. It is an informal meeting where Learning Disability information about services, events, difficulties and experiences are shared and useful contacts made .

Occasionally they have a relevant speaker such as Wiltshire County Council or the College. The Co chairs of the group can make representations to Wiltshire County Council about an issue of concern. The group would welcome the input of more Service Users and will support people to feel as welcome and supported as possible.

They will also be celebrating National Learning Disability week in June and have organised a fun day at Elizabeth House, Salisbury, where you can find out more about the support and exciting activity opportunities in and around Salisbury.

Also check the WSUN website for weekly dates and contact details for the chair of the group, Patricia Fagan, Manager of Elizabeth House or talk to members of the WSUN Development Team.

The meetings for 2014 are on the following Wednesday mornings 19th March, 25th June, 17th Sept and 10th of Dec between 10:30 - 12:30.

Service User involvement in Social Work Training

The degree course at Wiltshire College, Trowbridge is currently going through a re-design. The major change is that at the end of year one, students have to be assessed as ready to practice and the modules support the student towards this (previously done during the middle of year two).

The selection process for potential new students is also being looked at. The basis behind the changes is to increase the quality of applicants and to make sure as many students as possible complete the training.

Wiltshire College and the Trowbridge Hub are also looking at how they could broaden the range of users/carers involved with the programme. Service Users' form an important part of the selection process for students and also are involved in the training of students throughout the course.



Some of you may be aware that Roger Southard, Lecturer and Admissions Tutor for the Social Work degree at Wiltshire College is retiring at the end February after 15 years. We would like to wish Roger all the best in his retirement.

Our Time to Talk

Our Time to Talk continues to go from strength to strength under the leadership of Denise and Samiha; also with the support of WSUN. It has seen membership grow in recent months. The last meeting welcomed Steve Wheeler who is a Board Member of Healthwatch Wiltshire. Steve spoke about the role of Healthwatch and answered many questions. The group then shared issues about mental health services in Wiltshire and these will be included in a workplan, which will also set out what will be done to resolve issues.



Our Time to Talk meeting in March

We have received a good deal of interest in OTT recently and hope to welcome more new members to future meetings. Minutes from meetings can now be found on our web site. If you would like to find out more please contact WSUN.

World Mental Health Day 2014

Save the Date
Wednesday
8th October 2014
Corn Exchange
Devizes

- Stands
- Speakers
- Activities
- Refreshments

wsun
Wiltshire and Swindon Users' Network

To register your interest please email zoemillington.wsun@btconnect.com

A few days in the life... of Zoë Millington WSUN Development and Outreach Worker

Day 1 – A visit to Mere Day Centre (based in a sheltered housing scheme meeting room) to meet the guests and volunteers. We received a very warm welcome, due in some part to the fact that the sun was shining, and a birthday celebration was in full swing. After a short talk about what WSUN is, and does, and answered many questions, five new members joined the Network. The Good Neighbour Co-ordinator for Mere and Tisbury turned up and pointed us to three other local groups which she felt we should visit. Therefore another outing to the Mere area is on the horizon.



As a follow up to the visit, information about the forthcoming Health Forums was sent out and posters and newsletters were given to the scheme manager to take to other schemes in the area. We were also invited to call in again in a few months to maintain a relationship with the centre.

Day 2 – A morning of catching up on emails and suchlike. Then off to a Healthwatch event in Chippenham to gather information for the Our Time to Talk group and to get up to date with Healthwatch's work. I took part in some interesting round table discussions about ways of engaging with communities in Wiltshire. In particular, working age people with families, with whom it can be difficult to establish a dialogue with. This challenge is one which we hear many other groups and organisations face.

As is often the case at these events contacts were made. In this instance a new member for WSUN and Our Time to Talk who has a wealth of experience and is keen to work with WSUN in future.

Back to base for a quick cup of tea and then off into torrential rain to 'My Home Life' at County Hall, a project funded by Wiltshire Council, established to 'improve the quality of life of everyone connected with care homes for older people'. Essentially, to develop links between care homes and communities and for life in a care home to be stimulating and interesting.

The event was well attended by home managers, commissioners, and other key organisations. Discussions about what quality of life is and how it can be measured took place. The next step will be a community planning event which should take place in May. Both WSUN and care home managers stressed the need for home residents, families and carers to be part of the next step.

It was agreed that WSUN would be part of the next stage of 'My Home Life' and we were also invited to visit Marlborough Lodge Residential Home to meet some residents and their families.

Day 3 – A morning of writing Activity Reports about what I have been up to this week and telephone calls to arrange visits for the next couple of months. These will include information stands at libraries, a disabled and older people's sports event and attending the 'Open Minds' group coffee morning.



Neil Bartram from our Outreach Team (standing centre) with some of the residents of Greathouse, Chippenham

Neil and I then visited Greathouse, near Chippenham, a residential home run by Leonard Cheshire Disability. We spent a very enjoyable and informative afternoon with residents and staff. What struck me was not only the lively atmosphere but the absolute commitment of everyone that decisions are made by residents and that all residents are fully included. I did not get to the bottom of why there was a life-size cut-out of Liam from One Direction, (so Neil informed me), but that is a question for the next visit.

We were invited to return in April to have a stand at the pet show, along with pets, families, and friends. Definitely a date in my diary!

AWP Patient and Advice and Liaison Service (PALS)

“ WSUN has been a fabulous resource for AWP's Patient and Advice and Liaison Service (PALS) this year. They arranged for a service user representative to help us with a day of interviewing and focus groups. The input and perspective from this representative user was invaluable and instrumental in us recruiting our two new members of the PALS team.

A PALS officer also attended WSUN 'Our Time to Talk' and this joint working allows us to promote and explain our systems for raising complaints and concerns to service users.

WSUN have also invited us to have stalls at their World Mental Health Day event. Attending WSUN events gives us the valuable opportunity to speak to people about their care, whether good or bad, and to use this information to improve services or help individuals to progress their concerns. We have close links with WSUN, both attending the Wiltshire Mental Health Care Forum, where both WSUN and PALS discuss recent issues with Wiltshire Mental Health Services, and Trust Board events. ”

Jo Davis
PALS and Complaint Manager
Avon and Wiltshire Mental Health Partnership NHS Trust

'Mind the Gap'

The transition from childhood into adulthood isn't an easy one for any of us and for young people with learning disabilities and their families it can be a particularly anxious time. For a long time everyone seems to have known that, as far as services go, it can feel like 'falling off a cliff at eighteen years of age – at the very least there is a 'gap' that needs to be 'minded'. Wiltshire Council is trying to deal with gaps in provision by extending that transition period up to the age of twenty five, to give people a longer time to learn new skills, which help them to be more independent.

WSUN are working with the South Wilts Mencap '4&more' group to explore this theme by creating a short performance. The views of young people, including how they feel about their futures as they move into adulthood, will form the basis of a short presentation at a SW Mencap conference and this focussing on the 'transitions' theme. WSUN are exploring new ways of doing things and something of a pilot project for all of us involved, but we're hoping to make something that is simple to stage but still manages to be meaningful.

I'm aiming to make this project as open as possible, so if you or someone you know has experiences of stepping over that gap and if you'd like to share how your services helped or hindered you, feel free to drop me a line at the office and I'll come and chat to you to hear your views. You can email me at richardconlon.wsun@btconnect.com or call me on 01380 871007

Do you have some useful information that you would like to share with our members? Or is there something that you would like to know more about and see in future newsletters?

If so, we would love to hear from you. Please contact us on 01380 871800 or info.wsun@btconnect.com

Development Outreach Swindon

Swindon Mobility Club (SMC)

In our last newsletter, one of the topics discussed was the use of a Trampler mobility scooter in Coate Water, Swindon. One of our members recently requested to use this and discovered how it was not fit for purpose ie; flat tyres and not clean. We wrote to the Rangers at Coate Water of our concern. In reply they said: "I am sorry that this vehicle was loaned out to you in that condition. We pride ourselves in providing a valuable service to all our park users, and allowing everyone to experience the beauty of Coate Water.



The Trampler is kept in a store room, where temperatures do drop, and so makes the tyres deflate, but our team should have picked that up, and with it being a popular, free tool, many people use it. This time of year it can get dirty around its wheels, as it is crossing rough, muddy and wet ground. We try and keep it clean and well maintained."



Coate Water Park, Swindon ©Arwens Abendstern

If you would like to book the Trampler at Coate Water, please call the ranger and information service on: 01793 490150. Lydiard Park has a motorised scooter to enable you to access the grounds. If you would like to use this, please call: 01793770982.

The SMC coffee mornings are held quarterly at The Civic Offices, Euclid Street, Swindon. To find out when our next meeting is, please contact the office on 01380 871800 or email Swindon.wsun@virgin.net

Information

Support Group for People with Psoriatic Arthritis

PsAZZ is a support group for people with Psoriatic Arthritis (PsA) that was originally set up in 2011 by half a dozen or so patients of The Royal National Hospital for Rheumatic Diseases (aka 'The Min'). PsA is a debilitating form of arthritis associated with the skin disease Psoriasis. It can cause pain, stiffness and joint deterioration of varying degrees and many people who have Psoriasis are not aware that they are at risk of developing it. On average it affects up to 1 in 5 people with Psoriasis and most commonly affects the wrists and small joints in the hands - hence the choice of the PsAZZ hand logo.

Since the early days the group has grown to over 50 people who come from all walks of life and span areas such as Wiltshire, Bath, Bristol (although we have one member as far away as Scotland!) From the outset it has had the support of the Bath Institute for Rheumatic Diseases (BIRD) and Rheumatology Consultants & experts from The Min and the main aim has been to enable people with PsA to connect with others and share experiences. PsAZZ facilitates this means of mutual support through a range of activities such as bi-monthly meet ups, a quarterly newsletter and, more recently, the launch of a Facebook page. The meet ups are alternated between daytime/evening to allow as many members as possible to get together. In between meetings, Mel Brooke the group Chair, emails out updates and 'Topics of Conversation' so that everyone is kept in the loop and has a chance to interact even if they can't get to meetings or join Facebook.

For the last 2 years the group has run 'awareness campaigns' to let others know about the existence of the support group and to help raise awareness of PsA. It has also been highly supportive of the 'Save The Min' campaign and has begun to build links with other like minded groups such as The Psoriasis and Psoriatic Arthritis Alliance (PAPAA) who have a fantastic range of leaflets and a website full of information about Psoriasis and Psoriatic Arthritis. Through its connection with BIRD and The Mineral Hospital, several PsAZZ group members have begun working with rheumatology consultant groups across a number of PsA focussed initiatives that aim to help put patient concerns, and opinions, into the standardisation of disease measures and diagnostic tools - it's a positive move as many of the treatment plans for PsA stem from Rheumatoid Arthritis studies which, although similar, do not always cover the specific needs of the psoriatic arthritis population.

PsAZZ is more than happy to welcome new members to their group and, having recently joined WSUN are also looking forward to meeting other network members & groups.

Please see our website: www.psazz.webs.com for further information.



Sara Silks Group

In November, we visited the Sara Silk Group who meet at the Working Mens Club in Moredon, Swindon. This is a group for people suffering with Chronic Obstructive Pulmonary Disease (COPD) who meet every Thursday between the hours of 2.00pm-4.00pm. They have the opportunity to take part in gentle exercises at the start of the group and often invite guest speakers to talk about things they find of interest. We were invited to join in with the exercises which we found very exhilarating!

Afterwards, we spoke to the group about the work that WSUN does and gave them the opportunity to raise any issues they had regarding health and social care. We recorded the information, some of which was related to the Great Western Hospital (GWH), and sent this for clarification. The group wanted to know if there were longer waiting times at GWH now Cirencester Accident and Emergency closes at 9.00pm? We were advised that they haven't noticed any longer waiting times. We are still awaiting a reply to another question about how patients can get wheelchair services to assist them from the hospital to the car park. We will let you know as soon as we have received a reply.

Mobility Event

We were invited to have a stand at a mobility event at New College, Queens Drive, Swindon, last August, which we told you about in our last newsletter. They are hoping to hold another event this year, which we look forward to attending. We will let you know more details of venue etc when we have been informed.

Information

Wiltshire Home Library Service

The Home Library Service is for Wiltshire residents who want to read or listen to library books but have problems getting to their local library. This may be because of a disability, frailty, ill health or a short term need as a result of an operation.

A member of library staff will arrange a visit to discuss the kind of books you enjoy and then a volunteer will deliver the books on a regular basis, usually fortnightly. All volunteers have an enhanced disclosure check and the service is free of charge.

In addition, the library is also recruiting Home Library Volunteers. If you have time to spare, like books and reading and have a friendly, outgoing personality please get in touch.

For more information contact your local library or telephone Rebecca Bolton on 01225 713706 or email rebecca.bolton@wiltshire.gov.uk



Wiltshire Independent Travel Support (WITS)

This time of year, with Spring in the air (hopefully), you may be starting to think about getting out and about more. Wiltshire Independent Travel Support (WITS) can help you gain the confidence and skills to be able to access public transport and travel independently.

Carole contacted us as she wanted to be able to travel independently without relying on others. This meant Carole could organise her own week and possibly take on new roles.

With a long term medical condition, that necessitated the use of a wheelchair for the majority of the time when outside her home, Carole had not been able to go out without help for some time.

With support from the Travel Supporter, over a number of journeys, Carole became more confident and regained her independence. She is now volunteering for a local charity and has joined a local job club.



© Daniel MacDonald

Carole wrote in her feedback 'I hope you understand how grateful I am for being able to travel especially by myself!' The names have been changed to protect identities.

Can WITS help you?

To find out more about WITS please contact Peter North on 07806 935814 or email peternorth.wsun@btconnect.com

New Arrival

We would like to congratulate Gemma May, our Office Manager and her husband Jamie on the birth of Jacob Alexander May who was born on his due date of the 8th February weighing 7lb exactly.



Ongoing Opportunities to stay involved

For all details on up and coming events do visit our website page www.wsun.co.uk/events/ or call us.

Talking Newspapers

"The weekly Swindon & District Talking Newspaper (STAN) gives blind, visually impaired and listeners with other disabilities the independent means of keeping in touch with what's going on in the local community.

The Talking Newspaper is free to anyone who lives in the Swindon area and is unable to read newsprint for whatever reason." Contact details: 01793 522511

Other areas are covered and details can be found on the website www.tnf.org.uk



Rise in the Cost of Stamps

With stamp prices increasing again in April we would like to take this opportunity to remind all of our members that all invitations, letters and information is available by email.

If you would be happy for us to email you please send us an email so that we can keep you updated.

Contact Details:

**Address: Wiltshire & Swindon Users' Network
The Independent Living Centre
St George's Road
Semington
BA14 6JQ**

Tel: 01380 871800

Fax: 01380 871507

Email: info.wsun@btconnect.com

The Wiltshire & Swindon Users' Network is not responsible for information which is provided by third party organisations or agencies.

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NHS
Wiltshire
Clinical Commissioning Group

Wiltshire Council
Where everybody matters