

YPWD Newsletter

Our quarterly newsletter to keep you up to date with all things YPWD

Image from Walking Football



It's A Team Effort

A huge well done and congratulations to all of our participants for what you achieved at the Banana Triathlon, there was such a good atmosphere at the event, and the support from everybody made all the difference. We collectively raised an amazing...

£7493.00



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Welcome

Hello

My name is Jacqueline Riddles, and I am the Admiral Nurse working for YPWD covering Surrey Heath, NE Hants and Farnham. This is a new service and is due to be launched shortly following the success of the Admiral Nurse service in Berkshire, which has been established for many years. I am a registered General Nurse and Mental Health Nurse and have been working supporting people in their communities for the past 40 years! I am delighted to join YPWD and add to the amazing work they offer.

I look forward to meeting you all in the coming months and offering support for the families and carers of individuals living with young onset dementia.

Further information will be circulated once the service has been launched, including my contact details.



Four fabulous cyclists take on the 55 mile cycle from London to Brighton.

We would like to thank all our wonderful cyclists for cycling in aid of us, on the London to Brighton Cycle Ride 2023 - they all did it!

Well done and many congratulations!

You must all feel so proud - we certainly are on your behalf - we know how much time and commitment is involved in undertaking these challenges and to finally reach the finish line is fantastic.



Can we help?

Our empowerment group are looking for topics to discuss and action.

An example is, if you are struggling to find the way around your local doctors surgery, we can contact them, visit the location, assess the building, and propose new signage.

If you have an idea, please email jessica.vernon@ypwd.info

Ask the DOCTOR



Research update

How do you manage repetitive questioning?

Is there any medication that can help?

This is a great question and very much depends on the scenario and the level of distress that is being caused either for the individual living with dementia or family supporters. Listening to the same question many times in a day can be very tiring and lead to significant carer stress.

Repetition is, in fact, very common, particularly in Alzheimer's disease. So what is the best way to manage "Groundhog Day" as Karen Martin refers to it in her book "Memorable Loss"?

Applying normal logic simply may not work. For example, telling someone "you've asked me that before" will be ineffective, because their short-term memory store is leaky and they will have no recall of having said anything to you. Instead, you could consider what might be behind the question. Is it a need for information or an emotional need?

Often anxiety is an underlying factor with repetitive questions. For instance, someone might repeatedly ask "when is my appointment" or "where are you going"? In these cases, it may be useful to have information written on a whiteboard or in their diary if they refer to one. If anxiety about the unknown seems too overwhelming, then it may be better to give new information the day of the appointment.

Sometimes people just want to talk and have social connection so will use repeated questions and stories to command a conversation and retain a sense of identity. If you can predict what the repetitions are likely to be then you might be able to steer the conversation by introducing a new topic or idea or distract using pictures which may then widen the repertoire of conversations the individual wants to share.

There are no medications that are specifically licensed to reduce repetitions. Cognitive enhancing medication designed to improve memory, such as Donepezil, can have modest effects. Other options are medications to relieve associated anxiety.

If you are feeling stressed as a carer, remember there is opportunity to talk with others. Please contact the YPWD team for more information contact@ypwd.info.

There are as many different types of research project in dementia as there are reasons why people are keen to be involved.

Some examples of different studies that have run locally are

- Studies that seek feedback about your experiences of care and services
- Studies looking at the effect of environmental changes in dementia
- Studies looking at the effects of talking therapies in dementia
- Studies looking at the effect on new medications and treatments for dementia

People are keen to be involved, also for many reasons, but commonly people will say that they are keen to have the opportunity to help develop new treatments for future generations and also are keen to possibly get early access to new treatments for their symptoms.

In Berkshire there are two studies into dementia that will be starting

- 1) A questionnaire study for carers and family members asking about their experiences of caring for people with dementia and self-compassion. This will include families caring for younger people with dementia.
- 2) iACT for carers – this is due to open in the next few months and is a therapeutic intervention for carers based on ACT (Acceptance and Commitment Therapy) with online sessions with support from advisor

If you are interested in finding out more or helping with these studies, then you can either ask your Memory Clinic or contact our research team on Research@berkshire.nhs.uk

Indeed, if you would like to register your interest in future research studies you can also do this via the same email address Research@berkshire.nhs.uk

Participating in research will always be your choice, and hearing about potential studies does not obligate you to take part.

Padworth Woodcraft

»»» June to July west workshop

Written by Phil Redrup & Nosheen Khan



From hand drawn design

Our woodcraft workshop was located in the beautiful countryside of Padworth, in Royal Berkshire.

As everyone loves & enjoys sitting in their gardens particularly on sunny spring and summer day's, so we thought why not do a project creating cute wooden animal planters that our attendees can take home which will be nice as a decoration in the garden.

Attendees began the project by choosing their favourite animal. They then drew these out on a piece of card. From these designs, a pattern was drawn on thick card to act as templates to then be transferred onto pieces of wood, we added different layers and colours.



Phil helped the attendees to cut out their designs using the jigsaw. Once they were cut out, they had to be sanded down and painted.

There was always lots of laughter and chatter amongst the group whilst they worked very hard. It was great fun and everyone enjoyed it very much. We are all very proud of the final results. Absolutely fantastic.



Waltham Place Farm

»» July to September east workshop, written by Nosheen Khan

When we visit Waltham Place Farm we take the opportunity to walk and explore one of the most beautiful and best kept 17th century naturalistic gardens in Berkshire. Nicky who works at Waltham Place supports us with the activities from learning about the different wildlife that lives on and around the 220-acre farm and surrounding gardens to tasting some of the most delicious organic produce that has been grown on the farm. We are given the chance to help with weeding the ornamental gardens, getting to feel and smell all the different types of different herbs and produce as well as activities like apple picking from the orchards and feeding the pigs. We all find it delightful walking on beautiful pathways that lead us to many different secret gardens. There is just so much more to enjoy and explore at Waltham Place Farm that we all love coming back again and again.



Walking Football

»» July to September joint workshop, written by Richard Noakes



Football's coming home, it's coming home, it's coming, walking football's coming home!

And this Summer it certainly did come home to YPWD. We were put through our paces by our excellent coaches, who at first took us through a series of warm-up exercises in pairs. We then split into 2 teams and played out a spectacular finale!

Half-time refreshments included traditional oranges - just like the good old days!

Walking football is actually more difficult than normal running football, as it goes against your natural instinct to run. But everyone took to it like ducks to water.

Goal



Surrey Heath workshops

Written by James Goodman

Snooker and Pool

On Tuesday afternoons we chalked up our cues and headed over to Farnborough to hone our pool skills. We quickly discovered that snooker/pool was a pastime for a few members of the group, so it was great to be able to learn from one another and share stories from the past. We had a fantastic six weeks polishing up on some old skills, getting the competitive juices flowing and, as always, having some laughs along the way.



Art Appreciation

A fan favourite over in Surrey! During this six week block we were focussed on various floral designs using an array of different techniques and types of paint.

We began using water colours to produce some beautiful sunflowers, before trying our hand at some bean art which was a lot of fun! In the weeks to follow it was dot art on the agenda, where we experimented using cotton buds in place of our usual paint brushes.

Overall, we've created some really unique pieces over the six weeks and have been in great company doing so. Spirits are always high, whether we're having a sing song whilst we paint, or just a chat over some tea and biscuits, our art sessions have always left us with a smile on our faces.



Katakanuing

Over on the Surrey side of YPWD we have been out on the water at Horseshoe Lake doing katanuing. Over the 6 weeks we have had some good laughs between learning how to move the katanu in one direction and working our way up to being able to turn and zigzag our way through the lake. This came in especially handy for our scavenger hunts which got competitive to say the least! All in all everyone said how much they enjoyed paddling. And we certainly weren't expecting to have a workout each time—we are really going to hone those muscles!



»»» Written by Joe Hopper

Sunshine Choir

We have loved being back with the Sunshine Choir over the past few months and have been working hard at writing our own song, using memories and words that we relate to YPWD to create the verses and chorus. We are looking forward to singing our song at the Christmas concert to rapturous applause!

Every session ends with a dance along to some of our favourite songs, which always creates lots of laughs and giggles from the group.



»»» Written by Clare Lynskey



Equine Therapy

For the past 6 weeks we have joined the Mane Chance Sanctuary team at their venue for equine therapy. Mane Chance works with local farms, governments, and various organisations to ensure horses who have been neglected are rescued and recovered to ensure their welfare is maintained in a civilised manner. The sanctuary team had told us various stories of how the horses were previously treated and why they always try to go the extra mile for their horses.

Our group got to spend some weeks meeting and stroking the horses, but also creating a horse enrichment bag. These were old horse feed bags that we then cut 4 holes out of to act as a way into the bags. On the inside we stuffed them with hay, leaves, cumin, and mint which the horses thoroughly enjoyed. These bags were given to the Shetland ponies whereby a crowd favourite, Mr Smith, devoured it.

Later on within the set, we once again prepared a miniature feast for the horses, but this time in the form of a pellet mix. This meant that the pellets would absorb water when mixed and would hydrate the horses to keep them cool. Through this we were introduced to Berry who was the head of a heard and had a spectacular talent of flipping buckets.

In addition to the horses, the sanctuary also has various animals located on the farm. These range from goats, to chickens, and of course the farmyard dog - Angel. Our group was able to sit and stroke a couple of chickens which were safely stored away from Angel.

The team then went on to help with various jobs around the site which included composting and picking fruit. The compost was brewed for roughly a year and then spread accordingly around the farm, onto the flower beds. When picking the fruit, we picked two different sets: plums and apples. The plums were used to make jams and chutneys whilst the apples were used to make cider. Both of these goods are available in their shop whereby they also sell free range eggs, spreads and handmade decorations.



Written by Joe Hopper

MAKING MEMORIES

In June, we launched the Making Memories Scheme, which was made possible by the support of seed funding from Bearwood Lakes Golf Club.

Making Memories funds wishes that help people with a diagnosis to enjoy a unique experience of a lifetime. Our aim is to grant a wish to a person that we support with a young onset dementia diagnosis every month of the year. This wish could be for the person themselves, or to experience with their partner or family. Wishes can be anything from a skydive, a train journey across the country, learning to play a musical instrument, or watching the breath-taking beauty of a sunset from a hot air balloon. Whatever each winner's wish is, we will do what we can to make it a reality.

Our July 2023 Winner



When Chris was chosen as our July winner of a Making Memory Wish, one thing that kept cropping up in conversation with his wife Natalie was his love of driving. Unfortunately, Chris has not been allowed to drive since his diagnosis, but over the years he had owned Land Rover Discoveries which he and his friends would take off roading all around the country. After some thought, Chris and Natalie decided that he would like to take part in a **4x4 Off Road Challenge & Rally Stage Passenger Experience** with the chief instructor at Silverstone Rally School, which was arranged by YPWD.

Read below to hear about Chris' eventful day on Wednesday 16th August. This was written by his wife Natalie:

"To begin our experience, Chris was introduced to the team, and we were especially pleased to meet Karl Johnston who was the professional instructor and driver for the day. Karl has a vast knowledge of rally driving, he trains stunt drivers for movies and has worked with many well-known names. The Rally School is

located over the road from the famous Silverstone Motor Racing Circuit.

Karl went through a few safety checks and briefing with Chris, then they hit the track in a Sierra Cosworth rally car. They did a few fast laps of the circuit to warm the car up, apparently. Karl then showed Chris some neat tricks he could do, like donuts, parking the car sideways between two bollards and loads of skids, wheelspins etc. Chris loved it! The noise was deafening, dust was blown everywhere, but watching them was captivating.



Karl and Chris then swapped cars for a smaller option, a Nissan Micra, small but very powerful. Karl did similar types of tricks and even did the entire course backwards at speed, it was amazing to watch! Chris eventually exited the car with wobbly knees, at one point he needed to sit down due to all that adrenaline. He absolutely loved it, he had a break and joined my Mum and myself for some tea and cake on the veranda, while Karl prepared the next car.

A Suzuki Vitara 4 x 4, this was a much gentler car with regards to the speed, but a more challenging experience as they hit the off road course, Chris loved this part, as he used to go off roading back in the day, he and his friends would go off for weekends in Wales completing all the green lanes, he would come back covered from head to toe in mud and talk about it for days. This particular event brought all those memories back for Chris, he got a little tearful while reminiscing, but his smile said it all! Thankfully only the car was covered in mud this time.

Once the day was over and we said our goodbyes we walked over to the Silverstone Motor Racing Circuit, we were allowed on to part of the track (thankfully it was closed for racing that day) and had a few pictures taken, we toured the gift shop and had a bite to eat in the cafeteria, fully refreshed and ready for the long drive home - which was a much slower drive than Chris was used to at that point!

We want to thank everyone at YPWD for organising the day, and to Bearwood Golf Club for the kind funding to make this day possible, it was really appreciated.

Many thanks Chris, Natalie, and Mum (Maureen) x ""

BARN DANCE

»» Written by Debbie Lomas

We had a really fun time at our All Together Now event in July, which was a Wild Western Country Barn Dance set in the beautiful venue of Hillfields Farm in Upper Basildon, Berkshire.

When the guests arrived, through the gorgeous barn, they were welcomed and sat down to an Afternoon Tea of sandwich platters, sausage rolls, strawberries, cakes and biscuits, followed by soft drinks. We then headed off to the barn room to dance the night away. The relaxed atmosphere in the room came alive, and everyone donned their outfits and cowboy hats and boots, and with thanks to our Barn Dance Callers of the night, Ian and Ivan, we were shown and taught lots of moves and swings through the evening. The enjoyment on everyone's faces was just pure joy and fun for all!



BBQ



»» Written by James Goodman

On Sunday 17th September, Surrey held an All Together Now event in the form of an end of summer BBQ. In true British fashion, the weather was against us, but that didn't dampen our spirits! A feast was laid out and enjoyed by all.

Thank you to everyone that came, it was wonderful to get to spend time with you all.

We hope to see as many of you as possible at the Christmas Panto, our next All Together Now.



DORNEY LAKE BANANA TRIATHLON



On Saturday the 1st of July, our charity had a brave few individuals taking part in the Banana Triathlon at The 2012 London Olympic venue Dorney Lake which included swimming, cycling and running in the Novice, Supersprint, Challenge & Olympic events. We also had multiple teams working on separate disciplines to complete the triathlon in a joint effort.

The Banana Triathlon is one of the most inclusive events on the triathlon calendar, with distances for all experience levels. Because of this, we had many people taking part in their first triathlon to raise money for YPWD, and one of them shares her experience below:

“Waking up on the morning of my first triathlon event, my stomach was in knots. Luckily, I had packed my bag the night before and prepared my breakfast and food for the day, so I didn’t have much to stress over other than how nervous I was! My friends picked me up at around 7:30am to head off to Dorney Lake, while my mum and boyfriend set off in the van with our bikes. My mum was even more tense than I was, as she was taking part in her first Olympic triathlon event.

We arrived in the car park and had a 15-minute walk to the event village, where we collected our race packs. They contained a timing chip which needed to be attached to our ankles, numbered stickers that needed to be stuck on our bikes and helmets, and race numbers. We set our stuff down with the YPWD stand, where we met all of the other participants and waited together for our wave times. There was a lot of excited chatter and sharing of tips, snacks and hugs as each person gradually went off to begin their race. The first person to set off was Carol, participating in the Olympic Triathlon. Everybody watched as she made it into the lake to start the first discipline, which was an open water swim. Next was Benjamin, followed by Sabrina in the Challenge event, and then I realised the next person to go was me.

I docked my bike and set out my

towel, socks and trainers, helmet, and belt with my race number in the first transition point. Luckily, I met a group of girls who were also doing their first triathlon event, as everybody else seemed to know what they were doing, and I couldn’t even get my swim cap on! We headed to the side of the lake and had a safety briefing before the first lady in our event headed off in the water. This triathlon had a staggered start, which meant that we all went into the lake one after the other rather than everybody jumping in at once. This eased my fear of being kicked in the face. The water temperature was 21 degrees, and actually felt warmer than the temperature out of the lake as it was such a windy day. The water was clear and nice to swim in, although very choppy due to the weather conditions. I only had 400m to complete, so was in and out in around 9 minutes.

I had never done a triathlon transition before, so was weary not to break the rules, as if you touch your bike before putting on your helmet you become disqualified! I quickly took my wetsuit off and scrambled around until I was ready to head off for a 22km cycle. This was 4 laps of Dorney Lake. I was surprised to find the cycle the hardest discipline, and this was because cycling into the wind was so difficult. It felt like we were peddling and not moving anywhere, but a voice in my

head kept urging me to keep going. I bumped into Clare on the way, who was taking part in two disciplines for the team event and as we were chatting, I realised that in my rushed transition I’d forgotten to put my charity t-shirt on. Throughout the race I kept seeing flashes of green all around the course, as we had so many people taking part in the event for YPWD.



The last leg was a 5km run which I was unsure whether I’d be able to complete as I had developed shin splints. It’s amazing what adrenaline can do, as after not running for 6 weeks I was able to complete the discipline in under half an hour. During the run, the support from spectators and other participants was amazing, the atmosphere was electric, and there was no feeling like crossing that finish line. We were rewarded with bananas and isotonic beers.”

Written by Amy Pagan

If you are thinking about taking part in a triathlon and want to do it to raise money for a good cause, you would not regret it! It is an amazing experience and achievement. The tri season starts again next year from May onwards, so there will be plenty of time to train.

If you are interested, please contact julie.vernon@ypwd.info

Charity Fundraising

For Younger People With Dementia

Without fundraisers, our charity could not continue to run its services. There are so many ways you can fundraise for charitable organisations, whether that's climbing a mountain, participating in a marathon, or skydiving from 10,000 ft!

Richard participated in the Dorney Lake Banana Triathlon in July to raise money for YPWD as he has felt the benefits of the charity's support since his wife Sharon received a young onset dementia diagnosis. He discusses this in an interview below.



Which fundraiser did you take part in and when?

"The Half Banana Triathlon 1 July 2023."

Why was fundraising for YPWD significant to you?

"Since my wife Sharon's diagnosis last year, I don't know how we would have got through the past year without the YPWD. As well as offering practical, emotional help and support, we have made so many new friends. We also had concerns about attitudes towards dementia and being around so many positive people this fear of stigma has been completely dispelled."

How did it feel when you crossed the finish line?

"As with most people, it was probably an overriding sense of relief, especially as in the days leading towards it, I was carrying a hip injury and wasn't even sure I would be able to participate. But approaching the finishing line with my family and friends cheering me on was a big enough buzz for me to think - bring on the 2024 Triathlon!"

How much money did you raise?

"I set myself what I thought was an unrealistic target of £500 so was pleased when I saw it go up to £520."



Do you have any advice for others who are wanting to train to run a triathlon?

"I am so pleased I set myself the goal, although was glad I didn't give myself too big a challenge and went for the smallest event. As I swim and cycle regularly anyway, the run was the thing I was most concerned about. Although I started training (using the NHS app 'Couch to 5k') three months prior, I feel I probably should have begun a couple of months earlier. Having mentioned my hip injury, I think it was because I was pushing myself too hard a couple of weeks before the event and began skipping some of the rest days and wasn't giving my body time to recover. The moral of the story: listen to your body if it starts to complain!"

DIVERSE VIEW

»»» With Joanita Lwanga Winfield

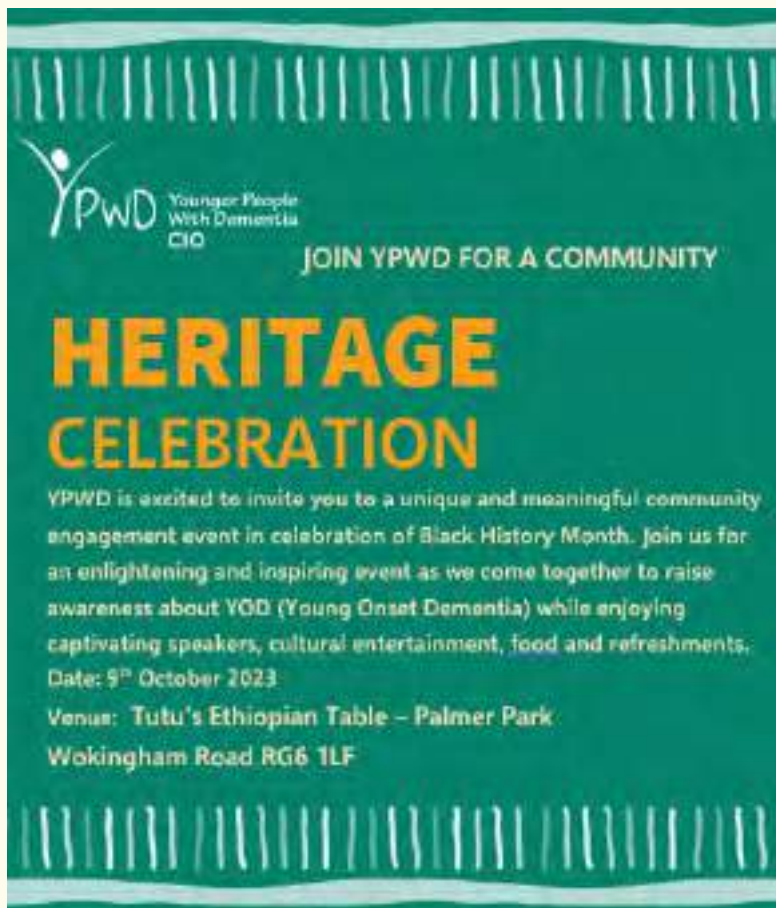
As seasons change, we embrace the change in time, daylight slipping away sooner and the nights becoming longer. It is easy, to think the change in time and season spells grey cold skies and long winter nights, but if one focuses on the impending winter season, it is easy to miss the magic we experience as we go through this change in season. Autumn brings a separate joy in itself, as the leaves slowly turn all shades of colour and fall off the trees, the months ahead promise all kinds of festivities, October to many spells Halloween, Divali and Black History month celebrations amongst many other events.

In keeping with the spirit of change, YPWD continues with various initiatives in championing engagement with ethnically diverse communities by continuing to raise awareness and help support people from all walks of life who've been affected by YOD (Young Onset Dementia).

Through the community outreach role, the scope and reach of services continues to evolve and develop innovatively to reach as many people as possible from diverse communities. There is continued partnership work with various stakeholders both in the voluntary and public sector to widen this reach.

To this end, YPWD will be hosting an online workshop in partnership with Slough Community Voluntary Service (CVS) on 26th September for various members in the ethnically diverse communities to continue to raise awareness of YOD and break down stigma in these communities. This will be hosted in partnership with Louise Costello YPWD Admiral Nurse.

As previously mentioned, YPWD endeavours to see that no one is left behind, adopting an inclusive approach whilst addressing YOD in diverse communities. By actively listening to diverse voices, understanding the unique challenges they face in accessing diagnosis and support for YOD, YPWD will be hosting a celebration of heritage event on 9th October 2023 starting from 2:00pm at Tutu's Ethiopian Table. YPWD invites healthcare professionals, community leaders, policy makers and individuals to join us in fostering dialogue, sharing experiences and collaborating on solutions that address the diverse needs of our communities. By embracing diversity, we can pave the way for a more compassionate and inclusive society.



»»» Why attend:

- **Raise awareness:** learn about the unique challenges of Young Onset Dementia within the ethnically diverse Community and understand how we can collectively address them.
- **Celebrate Heritage:** celebrate the rich heritage of our diverse community through cultural performances and expressions of unity.
- **Expand knowledge:** gain valuable insights from guest speakers that can help you provide better support to individuals and families affected by Young Onset Dementia.
- **Connect and engage:** network with passionate individuals and organisations that are committed to making a difference.
- **Open Invitation-**this event is open and welcoming to all interested in learning, connecting and supporting widening access to supporting those affected by Young Onset Dementia. Please RSVP to secure your spot as seating is limited.

Email: joanita.lwanga-winfield@ypwd.info



BOOK LAUNCH

November 3rd, 5:30-7pm

Venue: The Bell Bookshop, 52 Bell St, Henley-on-Thames RG9 2BL



We are proud to announce the release of our latest publication 'Working All Hours,' our third in a series of reminiscence books inspired by and designed for younger people with dementia.

Take a trip back to the 60's & 70's and walk down memory lane as you discuss your memories of your workplace and of others. Whether you worked as a policeman, a teacher, a housewife or a secretary, 'Working All Hours' is sure to conjure up lots of memories, a great tool to aid discussion, conversation and of course, reminiscence.

A book that can be read & enjoyed by all with real therapeutic benefits.



With special thanks to The Bell Bookshop for hosting the launch & to The Alan Peterken Fund, Surrey Community Foundation Trust & The Woodley & Earley Lions for sponsoring this project.



www.ypwd.info

Calendar of Events



OCTOBER

Monday 9th, Tutu's Ethiopian Heritage Celebration

NOVEMBER

Wednesday 1st, Berkshire Connecting Carers Group

Friday 3rd, Berkshire All Together Now event

DECEMBER



Sunday 10th, Surrey Christmas meal and theatre trip

Tuesday 12th, Christmas Choir Concert

Monday 18th, FTD Support Group, virtual

Tuesday 19th, PCA Support Group

Wednesday 20th, Berkshire Connecting Carers Group



April 2024—Walking Challenge