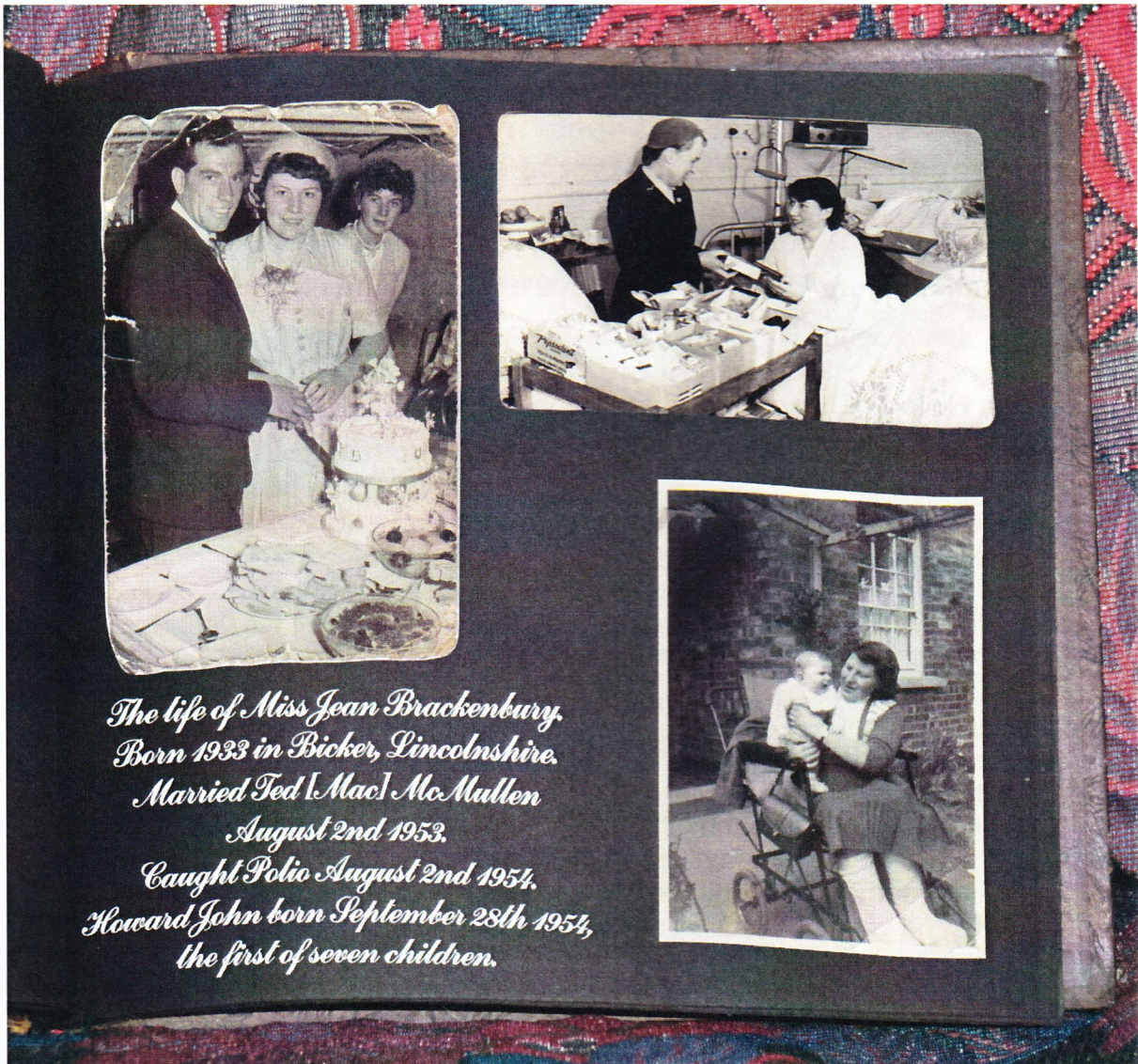




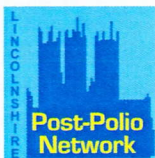
The LincPIN

The **Lincolnshire** Post-Polio Information Newsletter
Volume 6 - Issue 8 — March 2009

WebSite - <http://www.lincolnshirepostpolio.org.uk>



*The life of Miss Jean Brackenbury.
Born 1933 in Bicker, Lincolnshire.
Married Ted [Mac] Mc Mullen
August 2nd 1953.
Caught Polio August 2nd 1954.
Howard John born September 28th 1954,
the first of seven children.*



This publication is provided as a service to those seeking such information. The opinions expressed in this publication are those of the individual authors and do not necessarily constitute endorsement or approval by the Lincolnshire Post-Polio Network. ALWAYS consult your doctor before trying anything recommended in this or any other publication.

Lincolnshire Post-Polio Network - UK Registered Charity No. 1064177

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Our thanks to the following who have donated funds towards our work

Jim & Jenny Rayner, D.W. Rose, Ann Telford, Victor Gabriel,
Mrs. O. West, Winifred Hyam, Miss L.A. Forsyth, J.D. Witheridge,
Vivien Holland, Diana Nash, Lynn Hobday, Mrs. Y.S. Grosse, J.C. Dobbie,
Pauline Dunham, Mr. & Mrs. Darlington, Elizabeth Watson,
Frank Knights and John Ward.

Plus all those who work so hard for us for the time, energy and financial savings
donated to the LPPN from their PPS lives.

The Annual General Meeting. Saturday October 3rd 2009 in Lincoln

It has been decided to hold this on Saturday October 3rd 2009 in Lincoln, venue and speakers to be confirmed by the end of April. Information will be posted on our Website and our Members email list as soon as this is finalised. Anyone without access to the Internet who thinks they might be able to come please drop us a line and we will send you full details. This will also be printed in the next LincPIN, which should be with you in early July 2009.

CONTACT INFORMATION IS NOW ON PAGES 17 AND 18

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Editorial by Hilary Boone.

The clocks went forward today, the sky is blue and not a cloud in sight, the daffodils are bobbing in the light breeze and a couple of pigeons are making whoopee on the roof opposite. Methinks it might be Spring at last.

Yesterday I was contacted on Skype [a communication program on the computer where you can type to one another, talk and/or video phone for free with other users of the same program - www.skype.com] by Rosângela Rabel from Lisbon Portugal telling me about her campaign for Polio Survivors to receive more help. She put what I had typed into a translator to assist her in understanding exactly what I had said and then typed a reply in pretty good English. I will have to look into this as it would certainly make life easier to communicate with other Polio Survivors where English is not their first language. I went to Tesco yesterday and almost every aisle heard families conversing in Polish and other languages. Life in the UK seems to change so fast these days.

This newsletter contains part of the life story of Lincolnshire born Jean McMullen, nee Brackenbury. Her eldest son Jonathan Brackenbury has lodged copies of her tapes with the Lincolnshire Life Museum. He hopes to have these published as a book and/or made into a drama. With permission I have chosen to transcribe her life around the time she caught Polio in 1953. starting on page 8.

Lincolnshire. I am now into my eleventh year on the Lincolnshire Neurological Alliance committee and almost as many years of attending a variety of named meetings with the NHS and Social Services, one currently is the Lincolnshire Partnership Board for Physical and Sensory Impairment. It is sad to say that after years of working hard with other dedicated volunteers of medical charities that our biggest beef is that we continue to feel undervalued. Years of the Government decreeing that Service Users and Carers must be consulted on the constantly renamed and restaffed groups/trusts/departments committees. Years where far too many of us, across the country, are reporting back that we feel we were really only there so 'they' could tick the 'we have consulted box'. We sit at meetings with paid qualified and experienced staff claiming mileage and meal allowances as an unpaid volunteer often paying our expenses from our benefits. We often spend a lot of our valuable time and energy from our health reduced lives working on documents to see service improvements but how much intention 'they' have of actually taking anything on board we put forward is something many of us continually question. On top of this there are financial constraints. This year money is even harder to obtain. So many areas of the NHS and Social Services are competing for their share of the main pot of money we wonder what percentage of their plans are successful? If anyone has any suggestions how we might achieve more or knows of ways improvements have been made where they live then please let us know.

The rest of the country. We continue to receive reports and government documents and provide information relating to the issues our members are experiencing. I will be attending the Regional Neurological Alliance Meeting in Darlington on the 22nd and 23rd April 2009. I will be arriving at the Premier Inn Hotel on Morton Park early afternoon on the 21st April if anyone would like to meet up.

Post-Polio Health International Conference 2009 is being held at Roosevelt Warm Springs Rehabilitation Centre in Georgia, USA from the 23rd to the 25th April 2009. Due to overwhelming response registration is now closed. Unfortunately none of our UK members are able to attend this year. We will be receiving information from the event for the next LincPIN. Have any of our USA members registered?

Message from the Chair

With the improvement in the weather, there is real encouragement to go out and about. A number of events are coming up which should be really interesting, and I have listed some of them further down the page. But getting around isn't always easy! Small things, like getting the car filled up with fuel can be a real problem. Always a bit of an effort, I now can't do this for myself at all, and was restricted to topping up the tank only when I had someone with me who could do the job for me. Then I was introduced to something called ServiceCall.

ServiceCall is a system devised by Autochair to help disabled people call for assistance at Petrol Stations, Post Offices, Banks, Supermarkets and many other places. You aim a small infra-red transmitter to activate ServiceCall receivers in the windows of participating outlets, and a light on the transmitter flashes to tell you that your alert has been received. The receiver inside then beeps for about 5 seconds, warning the staff that you require service, and they then come out to help you. A sticker is supplied for your vehicle, so that you can be identified quickly, and an up to date list of all outlets will be sent with your order. Simple, effective, and best of all, it only costs a one-off payment of £9.95. (latest price information)

There are thousands of outlets using the ServiceCall system already, and more are being added every day. In fact - the more people who know about and use the system, the more common it will become. Drawbacks? Well yes, on one or two occasions, I've waited and waited for someone to come out to fill the car, but apparently the staff either haven't recognised what the beeping sound means, or the signal failed to activate the receiver, and I ended up having to drive on somewhere else to get my fuel. Autochair have a web-site where you can report problems like this, and they will do their best to resolve them.

If you are interested in this nifty little gadget, you can order it (using a credit card) on a Freephone number - 0800 214 045. Their web-site www.service-call.net gives details of every outlet using ServiceCall, and of course, you can order your transmitter from there as well.

BPF Expert Panel In January, I attended my first meeting of the Expert Panel in London. I found myself at a slight disadvantage, in that the discussion that day was about finalising items that had been discussed previously, and so my main function was simply to listen. It was good to be able to talk to other panel members prior to the meeting, and to get a firm idea of what the panel is trying to achieve at the moment. Now that a definition of PPS has been decided upon, information needs to be easily available to primary care doctors and other health professionals, so that they have a better idea of what PPS actually is, and where to refer patients to get the most effective treatment. Let's hope that better and more informed diagnosis will lead to better treatment and a greater understanding of the problems caused by PPS.

Meeting other members - There is always lots of laughter when Polio Survivors meet and share stories. If you are going to attend any of these events let us know by letter, email, phone and we will put you in touch. Why not hold an LPPN 'Meat and Greet' at a local hostelry where you live. We will let local members know by letter. NB June 20th in Lincoln.

21st April 2009 - Hilary will be at the Premier Inn, Morton Park, Darlington.

25th April 2009. 11.00 to 6.00pm

BPF East Midlands Super Forum at the Holiday Inn, Coventry. Speaker Professor Caroline Young from the Walton Centre Liverpool.

28th to 30th April 2009 10.00 till 5.00 [4pm on 30th]

Naidex NEC Arena, Birmingham. The UK's largest event for homecare, disability and rehabilitation. Naidex is your best opportunity to touch, test and compare all the latest new products and services available. This may be a chance for you to meet your Trustees, some of us will be there on Thursday.

For further information visit www.naidex.co.uk or ring (0)20 7728 4262

4th to 6th June 2009

Mobility Road Show 2009 - KEMBLE AIRFIELD, CIRENCESTER, GLOS

A showcase of mobility and lifestyle products and services, and a fun day out for all the family.

13th June 2009

BPF Super Forum at the Weetwood Hall, Leeds

20th June 2009

LPPN 'Meat and Greet' in Lincoln - Join other Polio Survivors, Family and Friends at the Lincolnshire Poacher, Lincoln, 11.00 to 3.00 pm. Lunch available from the Menu.

11th July 2009

BPF Super Forum at the Holiday Inn, Filton, Bristol.

The Western Region will be joining with Wales. Speakers, workshops, exhibitors and fun.

September 2009

BPF Super Forum. The South, including Home Counties. Venue and date to be arranged.

3rd October 2009 - Our Annual General Meeting in Lincoln.

24th October 2009

BPF Super Forum. Scotland, at Stirling Management Centre, Stirling.

Mary McCreadie. mary.mccreadie@lincolnshirepostpolio.org.uk

Driving Assessments Centres

The Regional Driving Assessment Centres [RDAC] (Birmingham, Oxford, Cannock, Hull) specialise in providing assessments for people who want to learn to drive or return to driving with a disability, or following a debilitating illness. The centre is staffed by a team of dedicated and experienced professionals - including specialist driving instructors and occupational therapists - and has a range of adapted vehicles permanently available, which can cater for a wide variety of mobility needs.

Even more now with an ageing population, people are wanting to drive until they are older and this places quite a strain on general practitioners who will be asked by patients about their ability to continue driving or return to driving, or for the general public who themselves have concerns regarding their mobility following an illness or general health.

We feel that this is where we are able to support all organisations who can suggest to their patients/clients that they attend the centre for a practical assessment of their ability to drive providing that they meet the current DVLA regulations of medical fitness to drive.

The fee for a driving assessment is subsidised, currently £80. The fee for a passenger assessment is again subsidised, currently £20. All fees are stated on the Application Form which can be downloaded from our website www.rdac.co.uk The website holds invaluable information that we hope you will find useful.

Our Centres offer four assessment and advice services. The information below will help you decide which of these is best for you. They each vary in how long they take and a different fee is charged for each service.

A full report is prepared after each service.

a) Driving Ability Assessment. If you have or have had a full licence, this assessment looks at both your ability to control the vehicle and to deal with traffic and other road users. It is for people such as those who have had a head injury or a stroke or who have dementia. It is advisable to bring another driver to accompany you on the day of the assessment. For people who have a physical disability and who need advice on car adaptations but do not need to drive from a wheelchair. We will give you an opportunity to try out equipment in our vehicles.

b) Driving Ability Assessment (Learner driver with Provisional licence).

This assessment is for people, who are concerned about beginning to learn to drive, who are experiencing problems with driving tuition or who have learning difficulties.

c) Specialist Vehicle Assessment for drivers. This assessment is for people who need high technology solutions, for instance those who need to drive from a wheelchair. This type of assessment will be suitable if you cannot transfer from your wheelchair or if you cannot stow your wheelchair on your own. We will give you the opportunity to try out equipment in an adapted Chrysler Voyager. Please note that cars can also be fitted with high technology equipment. To undertake this type of assessment you will require a valid driving licence, which can be either: Full, Provisional, or a Provisional Disability Assessment Licence. The assessment looks at both your ability to control the vehicle and to deal with traffic and other road users.

d) Passenger/Carer Assessment.

This service is for passengers who have difficulty getting in and out of a vehicle. The assessment explores a range of options including the use of specialist transfer equipment and wheelchair accessible vehicles. This service may also benefit carers who are experiencing difficulty assisting in the transfer of their clients.

Should you require any further information on our service please do not hesitate to contact me on 0845 337 1540 or via email either directly sreynolds@rdac.co.uk or info@rdac.co.uk if you would like us to post to you leaflets and a poster for display.

Sharon Reynolds, Advice & information Officer, Regional Driving Assessment Centre, Unit 11, Network Park. Duddeston Mill Road, Saltley, Birmingham, B8 1AU

DLA Awards continue after 65 years of age but be aware....

If a DLA award ends after you reach 65, you can make a renewal claim within one year of your previous award ending. If you leave it longer than a year, you have to claim attendance allowance (AA), which has no mobility or lower rate care equivalents. You can only re-claim your former rate of mobility component under this concession – you cannot switch rates after 65.

Care component – You can maintain or renew the lowest rate if you qualified for it before reaching 65. If your care needs lessen after 65, you cannot drop to the lowest rate – you will lose the care component altogether. You can, however, regain the lowest rate if you re-claim within 12 months of your previous award for it ending. If your care needs change after reaching 65, you can switch between the middle and highest rates or move up from the lowest rate, but you must satisfy a 6-month qualifying period. [DLA Regs, Sch 1, para 3(2)&(3)]

There is an exception that allows the DWP to drop you to the lowest rate even if you pass the disability test after age 65. This applies where the DWP decides you were not entitled to the rate you were getting before reaching 65 because the original decision maker did not know about, or made a mistake about, a fact in your case (rather than because your circumstances have changed). [CDLA/301/2005]

If you have the mobility component, a change in your care needs after you reach 65 enables your DLA award to be 'superseded'. This means you can claim the care component (at the middle or highest rate), rather than AA, even if you are aged, say, 70. You can still claim the lowest rate of the care component after 65 if you met the qualifying conditions before 65 and have a current mobility award made before 65. [DLA Regs, Sch 1, para 7; CSDLA/388/2000]

Mobility component – Once you reach 65 you can only stay on the rate you got before you were 65. You cannot move up or down a rate. But there is an exception to this rule. You can switch to the higher rate after age 65 if you can show that you met the higher rate conditions before age 65.

If you have a current award of the care component, made before you were 65, you can claim the mobility component after your 65th birthday if your mobility difficulties began before you were 65. If your mobility problems are such that you can only satisfy the disability test after your 65th birthday, you cannot get the mobility component. [DLA Regs, Sch 1, paras 1, 5 & 6; CSDLA/388/2000]

Disability Rights Handbook 33rd Edition April 2008.

My Polio by Jean McMullen, nee Brackenbury [transcribed from the taped story of her life].

I visited my married sister and her children. I had a niece, Margaret, who was five years old, more or less lived with us. In July I took her to Skegness where we sat at the side of the swimming pool all day. It was very hot weather. I was by this time seven months pregnant and been in very good health, but that day coming home on the bus from Skegness my head didn't ache... it thumped, more of a pain and I could not keep my eyes open. I was really ill by the time I had walked home from town.

When I arrived at home after walking from town I went to bed. Mac fetched the doctor next day he gave me medicine, he said it was my pregnancy and to rest. Days went by and I was so ill that mum brought the bed down into the front room as I could not get upstairs. The doctor kept sending me medicine. This went on for nearly three weeks. I was vomiting and everything I vomited was like black water. I was eating nothing but drinking a lot of liquids. My head still thumped with terrific pain. Everyone went on going to work so I was left on my own. I was 20 years old and eight months pregnant by this time. Mac fetched me a bottle of lemonade that morning before he went to work.

It was our Wedding Anniversary on August 2nd 1953. He went to work on the afternoon shift. At about 3.30 I wanted a drink but the lemonade was on a table across the room so I got off the bed to get it. I took three steps to the middle of the room and that was it, my legs collapsed and I could not get up. Dad came in for his afternoon cup of tea. He was only working in the field at the back of the house and he found me on the floor. He struggled and got me back to the bed and then went out to phone the doctor as we did not have a phone in the house. Within 20 minutes the doctor and the specialist came, examined me, scraped the bottom of my feet with pins and had a slight discussion at the end of the bed. Then it was all stations go and someone had to get Mac home. So Dad went down to the phone. Mac came home from work and within half an hour I was on my way to Lincoln Isolation Hospital. That was 50 miles away from my husband and family. This was August 2nd, my first Wedding Anniversary and I was so ill. I can vaguely remember my flowers and cards on the table which I had taken with me.

When I realised where I was it was like a row of glasshouses. I could see the patient in the next glasshouse but could not speak to them as they were all glass partitioned off. The sun was beating down, it was so hot, my head was thumping with pain. I was examined and had a lumbar puncture. Everything happened in the following two or three days. I could not pass water so the nurse would come with a needle, stick it in my leg and turn the tap on at the side of the bed but it never did the trick. I went through agony, it seemed never ending. First one doctor come in and then another. I was eight months pregnant and I think they were worried about my baby being born in that hospital. I did not know then it was polio. I don't think anybody ever told me. I must have been in that glasshouse for two weeks before they put me in a ward. I have learned later that there was an epidemic of polio.

There were so many children in that ward especially one beautiful little girl of about ten years old laid in an iron lung. Her mum used to come every morning and plait her long blond hair and put her different coloured ribbons on every day. She had her dolls and teddy bears around her which she could only see through the mirror but sadly she died.

I was put in an iron lung for three nights but I guess I was one of the lucky ones. I was only paralysed from the waist downwards. My husband was not allowed to come in the ambulance with me. He would travel 50 miles to see me and bring me flowers but was not

allowed past the gates. He brought me beautiful gladioli and I can remember them on my bedside table.

After a week in the ward I was transferred back to Boston General Hospital because the doctors did not want my baby to be born in the isolation hospital. At least I could now have visitors. I had seen no-one in three weeks. We had only been married a year so we were thrilled to see each other again. I stayed in the main general hospital for a month not getting any treatment. I suppose they could not do much as I was only a month off of having my baby.

So on the 22nd September I was taken down to the Maternity Unit not really knowing what was happening to me. My husband was allowed to visit me when he liked. He was working on the buses on shifts. Then he would come whenever he could. This was great really because I was shut in a side ward and was very lonely. Mum and Dad and my sisters would come but I never then realised that I would never walk again. And I don't think when I look back and think about it the doctors did not know how very badly I was paralysed and how my baby was going to be born or when it would be born. I had so many doctors coming to examine me and being my first baby and only 20 years old I just did not know what was happening. I had never been to an ante natal clinic so I was a bit naïve.

On the 27th September I suppose I could not be left any longer so the doctors decided to start me off in labour. I had feeling in my legs so when I had an injection on the hour every hour for 12 hours but nothing happened. I had terrific pains but still nothing happened. So on the next day, 28th September in the morning after laying all night in pain Mr. Lawrence, the Doctor, came and broke my waters. At six o'clock at night Howard John was delivered by forceps. He weighed 8lbs 12 ozs. and was a perfect baby apart from the marks on his face which wore off in a few days, which was caused by the forceps. My sister Madge was allowed to see me for a few minutes but after all I had been through in those last few weeks I just fell to sleep so happy with my lovely baby boy.

I stayed in the Maternity Wing for six weeks with Howard John in his cot at the side of me. My husband fetched his pram to the hospital and the nurses would bath him and put him in his pram outside for fresh air. We had to pay for all his nappies to be washed then. After six weeks I could not stay on the Maternity Unit any longer so it was decided that I had to go the Boston Orthopaedic Hospital at London Road but the main question was what to do with Howard John. My mum worked, my husband worked, so the only thing was to get him in a nursery but where? There was nowhere in Boston so it seems. There was a little one in a lovely village called Scothern near Lincoln. My husband took him to have his photograph taken and he went to that Nursery and I went to the Orthopaedic Hospital. We had to part. We were 50 miles apart not knowing when I was going to see him again.

I got settled in my new hospital which was all long stay and bed ridden people. I still hoped that I was going to get the use of my legs back. But as the weeks went by I don't think it ever sunk in that I was never to walk again. I had plaster boots made held on with thick bandages and eventually I had heavy iron calipers made and fastened onto some horrible brown lace shoes which we had to buy in them days again. There was no social security to buy these things for you. I had my legs massaged once a day and was taken to the gym to learn to walk on the calipers with crutches. When we came back from the gym we were put back to bed and stayed there until the next day. There wasn't the facilities that there are today. At night there were two sandbags at our feet to keep them from flopping about. I did ache with sitting all the time.

Another young girl called Rose, she was seventeen, came in just after me so we became

great friends. She was paralysed from the waist down but her legs were stiff, she couldn't bend them like I could. The polio affected us in different ways. Eventually we were given two very old fashioned wheelchairs so at least we could get around the grounds of the hospital and probably chat to the men in their ward or go and watch the children in their ward. Sitting all day didn't half make your back ache. So we were relieved when Nurse Lane would come and say to get back into bed and at least I could roll on my side for a bit of relief off my spine.

I had that Christmas in hospital and my 21st birthday in January. The only thing was I wanted to see my baby after five months. It seemed like years. So one weekend in February Mac hired a car and I was allowed to go. My legs swathed in plaster boots and bandages. He took me 50 miles to the lovely nursery. It was like an old farmhouse in a little village with flowers round the door. I sat in this room and the nurse brought Howard in, he was beautiful but it broke my heart because he didn't know me. I had not seen him since he was six weeks old and then he was nearly six months. We stayed about two hours then I had to part again. I had to go back to hospital to continue my treatment. I hated to try and walk on them cast iron calipers.

Winter came and went and then I had another shock my husband could not stand it any longer so he went back to live with his family up in Lancashire. I had nothing, no home, no baby and no husband. Only life in a hospital ward. I cried nights and days nobody wanted me.

My Dad and my sister did their best but what was I going to do? I did not know who to turn to. I don't think there were any social workers then to help you. Mac had nursed his mother from being 16 but she died with asthma so it seems that he was going to have to nurse me he just wanted to get away to sort himself out because it must have been a big shock me not going to be able to walk for the rest of my life.

So not knowing what I was going to do, I wanted my baby but no-one knew what to do with me. My mum didn't want us at her house. This went on till May. I had not heard a word from my husband until one day in May when the matron came with a letter. He wanted me and Howard out of hospital. Where were we going to live? I was virtually helpless with an eight month old baby. He had made up his mind so on one Sunday his oldest sister brought him down from Lancashire collected me from the hospital, collected Howard from Scothern nursery and we went to live with his sister in the front room.

There was no social services as I said then. If there was we had never heard from them. Today anyone like us then would have been given somewhere to live.

When we arrived at his sister's on the Sunday her front room was empty so naturally my husband had to go out to buy some furniture. So he bought a 'put you up' for us to sleep on and a cot for Howard and apart from one or two more little bits and pieces this is how we lived in the front room. I could not walk so I had to sit in a chair all day. Howard sat in his cot and my husband made him his sandwiches and a flask before he got work for I was helpless. My husband got work down the mine so that meant I was on my own all day more or less. I could not move about as I had to have someone pull me up on my feet and I could not sit down without the help of someone there. Them calipers were so heavy, big leather rings that dug into the tops of my leg. I also had to wear a corset with laces and buckles to strengthen my weak back

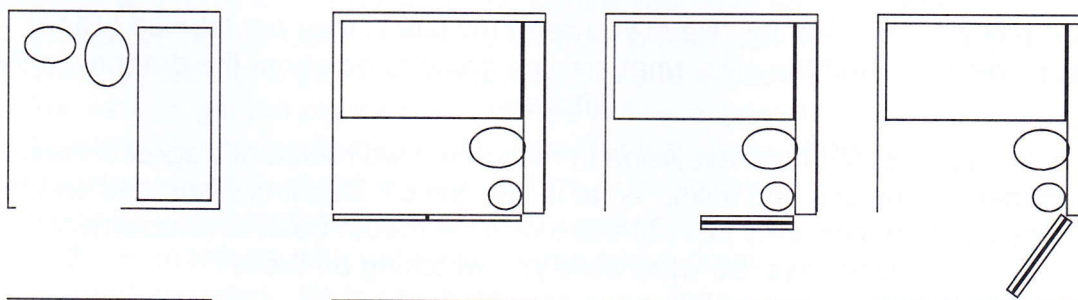
Mac was on shift work, 6-2, 2-10, 10-6 so I was on my own all day in that front room. I would just sit in the chair all the time while he was at work and if I wanted anything I would

get on the floor and slide on my bottom. Howard spent all the time in his cot. When Mac come home he would pull me up on my calipers and I would have a walk but I could only try and walk a few yards. The toilet was outside. I could just manage that. I then had to go back and sit in that front room till the next day I suppose my sister in law did her best but after three months she did not want us.

Jean was born on the 23rd of January 1933. She went on to have seven children [sadly one twin died in a drowning accident in the garden] She did all her housework from her wheelchair. She died in 2006. Jonathon Brackenbury, her eldest son has given us permission to use this excerpt from her life story. He hopes to have this published or made into a drama. No reprints of this article are allowed without his permission in writing.
Jonathan Brackenbury, jmacbracken@hotmail.com

Bathroom alterations. As we age and our needs change you too might be looking at changes for your bathroom. Sadly in current times professionals that have to make decisions on what alterations and/or equipment is best for you have to consider cost. Their advice may be based on cost rather than what would work best for you now and in the future. You need to do some research on what is available and if at all possible go and stay in places where you can try out the different options. In the UK the stock response seems to be you can have a bathlift if you have a bath but if you are going to make alterations then 'because you are disabled you need a wet room'. You need to consider other people who live in the home and that you might need extra equipment and/or physical help in years to come. Whilst a flat floor shower might give you more room to manoeuvre if you use a wheelchair will you miss soaking those aching muscles which is so beneficial to our health and wellbeing? When being assessed by an Occupational Therapist it is essential that you demonstrate how you move about because you may not fit their norm. Many polio survivors push up on their arms because they don't have the strength to pull up. Rails often need to be far lower down than expected by those advising and/or fitting them. Remember you can move differently when wet so put on a swimming costume before you have rails fitted to ensure they are in the right place.

It all boils down to how much room you have to work with. Draw a plan to scale and cut out baths, toilets and sinks, shower tray sizes, wheelchair turning circles, bath hoist, and don't forget to cut out a block for a person that might need to be in the bathroom with you. If your bathroom is not very big then you might be able to do what we did. For more room we changed the design, fitted a new 1000mm wide bath, and hung on wall toilet and sink. We hinged two doors in the middle as you can see from the diagrams below. If needed we can open the doors up fully and add the hall space to the bathroom. We received a Disabled Facilities Grant to do this.



Jim's Pages to Make you Smile

Why - by Pauline, Polio friend from Cumbria

Oh, why do people stop and stare,
When seeing me in my wheelchair,
I'm just like other human beings,
With the same kind of feelings,
I think and feel just like you,
I do most things that you can do,
I do not live a life that's dull,
I try to make it really full,
Please think of me on a level par,
Then I am sure we can go far,
Although my limbs don't work quite right,
My mind is really very bright,
So please don't judge on what you see,
Look inside and see the real me.

New Diet

Yesterday I was buying 2 very large bags of Purina dog chow at the store for my dogs Winston, Chief, Gus and Maximus. I was about to check out when a woman behind me asked if I had a dog. What did she think I had an elephant.

On impulse I told her that no I didn't have a dog and that I was starting the Purina diet again, although I probably shouldn't because I ended up in the hospital last time. On the bright side though I had lost 50lbs before I awakened in the Intensive Care Ward with tubes coming out of every hole in my body and IV's in both arms.

Horrified she asked me if I ended up in Intensive Care because the dog food had poisoned me. I told her, 'No, I had stopped in the middle of the parking lot to lick my butt and a car hit me'. I thought the guy behind her in the queue was going to have a heart attack he laughed so hard.

If they can put a man on the moon why can't they make knickers that fit?

We put in our two cents, but only get a penny for our thoughts. What I want to know is who gets the extra penny?

An elderly couple was attending church. About half way through the wife leans over and whispers to her husband, 'I just let out a silent fart, what do you think I should do?' He replies, 'Put a new battery in your hearing aid'.

A boy asks his Granny, 'Have you seen my pills?, they are labeled LSD.'
Granny replies, 'Stuff the pills, what are you going to do about the dragons in the kitchen'

Little Billy asks his Dad for a television in his room. Dad reluctantly agrees. Next day Billy comes downstairs and asks, 'What is love juice?' Dad looks horrified and tells Billy all about sex. Billy just sat there with his mouth open in amazement.

Dad says 'So what were you watching on the tv?'

Billy says 'Wimbledon'.

Tongue Teasers

1. Freudian slip is when you say one thing but mean your mother.
2. A pessimist's blood type is always b-negative.
3. A hangover is the wrath of grapes.
4. A successful diet is the triumph of mind over platter.
5. A gossip is someone with a great sense of rumour.
6. A chicken crossing the road is poultry in motion.
7. A boiled egg in the morning is hard to beat.
8. Corduroy pillows are making headlines.
9. Shotgun wedding: A case of wife or death.
10. Marriage is the mourning after the knot before.
11. Acupuncture is a jab well done.
12. Santa's helpers are subordinate clauses.
13. Every calendar's days are numbered.
14. Those who jump off a Paris bridge are in Seine.
15. Is a book on voyeurism a peeping tome?
16. Does the name Pavlov ring a bell?
17. What's the definition of a will? (It's a dead giveaway.)
18. Sea captains don't like crew cuts.
19. Energizer Bunny arrested -- charged with battery.
20. Dijon vu -- the same mustard as before.
21. When two egotists meet, it's an I for an I.
22. When a clock is hungry, it goes back four seconds.
23. When you dream in colour, it's a pigment of your imagination.
24. When an actress saw her first strands of grey hair, she thought she'd dye.
- 25.. A man's home is his castle, in a manor of speaking.
26. A man needs a mistress just to break the monogamy.
27. A bicycle can't stand on its own because it is two-tired.
28. In democracy your vote counts. In feudalism your count votes.
29. A lot of money is tainted. It taint yours and it taint mine.
30. Time flies like an arrow. Fruit flies like a banana.
31. She had a boyfriend with a wooden leg, but broke it off.
32. He had a photographic memory that was never developed.
33. Bakers trade bread recipes on a knead-to-know basis.
34. You feel stuck with your debt if you can't budge it.
35. He often broke into song because he couldn't find the key.
36. The man who fell into an upholstery machine is fully recovered.
37. A grenade thrown into a kitchen in France would result in Linoleum Blownapart.
38. Show me a piano falling down a mine shaft, and I'll show you A flat minor.
39. Once you have seen one shopping centre you have seen the Mall.
40. The short fortune teller who escaped from prison was a small medium at large.
41. This guy fell into a glass grinding machine and made a spectacle of himself.
42. Those who get too big for their britches will be exposed in the end.
43. Marathon runners with bad footwear suffer the agony of defeat.
44. Dancing cheek to cheek is really a form of floor play
45. Reading whilst sunbathing makes you well-red.
46. With her marriage, she got a new name and a dress.
47. Without geometry, life is pointless.

Hello Everybody, my name is Glenna Tomlin. I am a relatively new member of the Lincolnshire Post Polio Network, just three years. Last year, Lynn Hobday, Jim Pullen and I joined the committee as Trustees to offer some assistance to Mary, Hilary, Denise, Ruth and all the others who work so hard for the LPPN.

I used to work for Social Services and one of my first duties is to write a reply to Lynn Hobday's article describing her daily battles with the authorities who have been helping her since the sad death of her husband. I thought that it would be best to write a little about myself first, which I hope you will not find too boring.

I had polio as a child leaving one arm partially paralysed and a weak leg, but I was fortunate and recovered fully apart from the arm, or so I thought, until problems started in what I had always considered my good limbs. On leaving school I commenced my career in nursery nursing in Ipswich, Suffolk and was able to study for the NNEB qualification, which I subsequently passed. Through all this period I had great support from my polio consultant Mr Mayon White.

After I successfully passed these exams I worked on the Children's and Maternity wards of the Ipswich and East Suffolk Hospital. Despite the fact I could never raise my right arm above my head or lift a teaspoon to my mouth I managed all working duties including lifting babies. Life continued as with most people, marriage, children and at one stage for extra money I undertook child minding. At this time my left good shoulder started playing up - probably due to the continual lifting of children and the numerous walks to and from school, with pushchairs, to pick up other children also affected my back and legs, although I always tended to ignore these aches and pains.

About this time I divorced my first husband and subsequently met my present husband and with his encouragement decided to retrain as a Social Worker. Initially I started part time at College and also worked as a volunteer at a NCH respite home for children with a learning disability aged 5-19 years.

A full-time position eventually came up for a project worker for which I applied, successfully and continued to work whilst I studied for my degree. After obtaining my degree, I successfully applied for a senior's position still within the project. Sadly, shortly after this my manager died from cancer and I was made Acting Manager of the project which lasted for three years. This proved to be most stressful having to create business plans etc. and trying to run a service on less amounts of money each year. I found that I missed the contact with the young people. When finally a Manager was appointed I was happy to be Deputy Manager again for a short while but realised that the work was too stressful, heavy, and some of the young people could be very difficult to manage resulting in staff injuries. I became aware that I was causing myself excessive damage and was always exhausted by the time I had finished a shift. Being on call at times meant you could never relax. Though I loved the work and really missed the young people I decided to retire at 60.

My reaction, when asked for my thoughts on Lynn's predicament was, 'That's not my sort of Social Work'. Although I have worked in partnership with Schools, Social Services and Parents I can only really give my thoughts on the matter. I felt great compassion for Lynn who I have realised is a feisty lady. I feel the authorities, especially the Social Workers, have failed Lynn by not understanding the physical and emotional effects of grief and bereavement. This is surprising as it is a general part of training for all Social Workers. Also the effect of post polio syndrome, would have made her condition much worse

Continued on page 17.

If it's not one thing - then it's another

A little over two years ago, I received a call from my GP asking me to make an appointment to see her. I was puzzled and a little worried as I had seen her only recently.

I attended on the date given and was informed that my recent blood tests [to monitor my kidney problems] had shown that I had Type 2 Diabetes. This was explained as non insulin dependent and was usually controlled by diet and exercise or, sometimes, by diet and tablets.

I was astonished! How did this come about? I was feeling well and not very tired. Although I had been having regular blood tests, somehow I had 'slipped through the net'.

My next question—what had caused it?

I should have realised—good old polio raising it's ugly old head—this time in another form, walking less. Is there no end to it's versatility? Diabetes occurs through being overweight, lack of exercise; and sometimes because it is in the family genes.

Let me go back a few years to give you some background and to tell you what I was so cross and why I felt let down by the NHS.

I had a very bad fall resulting in two operations on my paralysed leg. Four months of immobility and then discovering that I could walk only a few steps with great difficulty and a walking frame. So now I have to use a wheelchair; am unable to get exercise. I knew that I would likely now put on weight and this would bring other problems so I went back to my GP to ask for help and advice. She was sympathetic, but not very helpful. She knew of no facilities that could provide exercise for those with such limited mobility. The nurse suggested that I join a Health Club. Good idea—so I tried. They were willing to accept me as a member so that I could use the swimming pool. Problem was I was unable to walk from the changing rooms to the pool and at that time there was no shower chair available.

Physical inactivity causes many problems for polio survivors, and diabetes is high on the list. If, through no fault of your own, you are aware of a thickening waistline, and are unable to get enough exercise, then reassure yourself by going to see your GP and ask for a blood test. This pesky diabetes can creep up on you without your having any symptoms—and then there is another problem for you to cope with.

If, unfortunately, the test results come pack positive, then you can get all the information you will need from Diabetes U.K. at 10 Queen Anne Street, London, W1G 9LH. Telephone 020 7323 1531, Fax 020 7637 3644. Email info@diabetes.org.uk. Website www.diabetes.org.uk

[Editors Note - I know that most of us have enough to cope with and the last thing they want to read is about another condition! However, even though I know the author of the above I did not know she had Type 2 diabetes, I did not know that you could get this without symptoms [weeing a lot and feeling dizzy were the only two symptoms I knew to look out for which I do not have] I have just had a huge shock to find I too have Type 2 diabetes. I have therefore taken the decision to include a few facts on the next two pages and the back page a guide to a balanced diet.]

A few facts from www.diabetes.org.uk

What is diabetes?

Diabetes mellitus is a condition where the amount of glucose in the blood is too high because the body cannot use it properly. Glucose comes from the digestion of carbohydrate containing food and drinks and is also produced by the liver.

Carbohydrate comes from many different sources including starchy foods such as bread, potatoes and chapattis, fruit, dairy products, sugar and other sweet foods.

Insulin is vital for life. It is a hormone produced by the pancreas and helps the glucose to enter the cells where it is used as fuel for energy so we can work, play and generally live our lives.

Diabetes types

There are two main types of diabetes. These are Type 1 and Type 2.

Type 1 - diabetes develops if the body is unable to produce any insulin. This type of diabetes usually appears before the age of 40. Type 1 diabetes is the least common of the two main types and accounts for between 5 and 15 per cent of all people with diabetes. You cannot prevent Type 1 diabetes.

Type 2 - diabetes develops when the body can still make some insulin, but not enough, or when the insulin that is produced does not work properly (known as insulin resistance). In most cases this is linked with being overweight. This type of diabetes usually appears in people over the age of 40, though in South Asian and African-Caribbean people, often appears after the age of 25. However, recently, more children are being diagnosed with the condition, some as young as seven. Type 2 diabetes is the most common of the two main types and accounts for between 85 and 95 per cent of all people with diabetes.

There are currently over 2.5 million people with diabetes in the UK and there are more than half a million people with diabetes who have the condition and don't know it.

If you are white and over 40 years old, or if you're black, Asian or from a minority ethnic group and over 25 years old and have one or more of the following risk factors, you should ask your GP for a test for diabetes.

The risk factors

- A close member of your family has Type 2 diabetes (parent or brother or sister).
- You're overweight or if your waist is 31.5 ins. or over for women; 35 ins. or over for Asian men and 37 ins. or over for white and black men.
- You have high blood pressure or you've had a heart attack or a stroke.
- You're a woman with polycystic ovary syndrome and you are overweight.
- You've been told you have impaired glucose tolerance or impaired fasting glycaemia.
- If you're a woman and you've had gestational diabetes.
- You have severe mental health problems.
- The more risk factors that apply to you, the greater your risk of having diabetes.

Travelling.

Always let your travel insurance company know that you have diabetes – not doing so may mean that your insurance is invalid.

Services in your area - <http://www.diabetes.org.uk/InfoBankUK/>

Editors comment - The government state that 'routine testing provided by a systematic screening programme for those at risk of Type 2 is **encouraged** as the best way to diagnose diabetes at an early stage before complications develop'

Is this available in Lincolnshire? - Yes. However, the word is 'encouraged' not mandatory.

Polio Survivors with PPS and reduced ability to function would be better able to manage our lives if we had a yearly health check. The earlier you are aware of new issues, the sooner you can do something about it.

Food is now packaged with lots of information including Calories, Protein, Carbohydrates, Sugar and Salt content. Why not make a small chart and record what you are eating for a day. You might get a shock like I did because I found it easier to make some of my five fruits a day, diluted fruit juice...but by the PINT and two a day and 104%+ of advised level of sugar for the day. That was just what I drank. Food on top of that, sheesh!!! Changing what we eat and buying digital scales where lbs are also divided by five has resulted in a small but regular weight loss.

Balanced Diet - See back page for a rough guide to what you should eat. Note that everyone is different and this is just a guide.

Continued from page 14

Was there not someone who could have co-ordinated all these appointments and established which adaptations were most important for Lynn? And could not that person have contacted her Social Workers and reminded them that she was grieving for her husband and making decisions at this time would be difficult for her? Was it not possible to have the work done in stages so it was not so overwhelming? I find it very difficult to comment on something when you cannot see what is being done and you do not see both sides of the equation.

My husband and I sorted out adaptations for my mother-in-law's central heating, stair lift, and an outside wheelchair lift. She grumbled that she did not want the noise and mess but afterwards said how the workmen were very good and cleared up all their mess. The adaptations were finally handled by a company recommended by Social Services called 'Anchor Staying Put' who specialise in this field, and a small percentage is charged out of the grant. We did not live near enough to be of much help, so one lady was appointed from this company who organised everything with my mother-in-law.

In conclusion though I think we have to remember Social Services are trying to do a job which at times is difficult. Perhaps, therefore, it would be a good idea to ask Social Services to attend one of our meetings so there can be a two way exchange of information and there is a better understanding of both sides, which might go a long way to avoiding anyone else suffering Lynn's experiences.

Glenna Tomlin - glenna.tomlin@lincolnshirepostpolio.org.uk

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why not support our work by joining us

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If you do not wish to cut the newsletter
then please copy the information to a letter. Thank you.

LINCOLNSHIRE POST-POLIO NETWORK

A Post-Polio Information Service for Polio Survivors and Medical Professionals
Registered Charity No. 1064177

Website - www.lincolnshirepostpolio.org.uk

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EMAIL info@lincolnshirepostpolio.org.uk

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Or email:- membership@lincolnshirepostpolio.org.uk

Cheques Please make payable to 'Lincolnshire Post Polio Network'

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[Post US\$ checks to LPPN - c/o 4212 Blanding Blvd, Jacksonville FL 32210]

Other Please contact membership secretary.

Newsletters - The LincPIN - Next Issue June 2009

Articles/Items/Tipbits/Letters/Questions must be received by 21st May 2009
Post or email:- newsletter@lincolnshirepostpolio.org.uk

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REMEMBER - DONATIONS TOWARDS OUR WORK, LARGE OR SMALL, ARE WELCOME

Your daily balance

Following a healthy eating pattern means eating foods from the five food groups in the right proportions. To get an idea whether you are hitting the mark think about how many portions of each of these foods you normally eat and see how it compares. Remember everyone's nutritional needs are different and you may need more or less portions than those suggested



Remember...

If you are trying to lose weight the sizes of your portions may need to change...check for more specific advice with your dietitian

Food groups and what's in a portion

Bread, cereals, rice, pasta and potatoes

- 2-4 tbsp cereal
- 1 slice of bread
- half small chapatti
- 2-3 crispbreads or crackers
- 2-3 tbsp rice, pasta, cous-cous, noodles, mash potato
- 2 new potatoes or half a baked potato

Fruit and vegetables

- a whole banana or apple
- a slice of melon
- 2 plums
- a handful of grapes
- a cereal bowl of salad
- 3 heaped tablespoons of vegetables

Meat, fish and alternatives

- 2-3oz (60-85g) meat, poultry or vegetarian alternative
- 4-5 oz (120-140g) fish or oily fish
- 2 eggs
- 2tbsp nuts
- 3tbsp beans, lentils or dahl

Milk and dairy foods

- 1/3 pint milk
- small pot yogurt
- 2tbsp cottage cheese
- 1 1/2 oz cheese (40-45g, matchbox size)

Fatty and sugary foods

- 2tsp spread, butter, oil, salad dressing
- half a sausage
- rasher of bacon
- 1 mini chocolate bar
- 2tsp sugar, jam or honey
- 1 scoop ice cream or 1 tbsp cream
- half pack of crisps

How many portions should you eat in a day?

7-14

Include starchy foods at all meals. Choose more slowly absorbed varieties whenever possible (see page 4)

5-9 or more

Choose a wide variety of foods from this group, including fresh, frozen, dried and tinned.

2-3

Choose the lower fat alternatives whenever possible and eat more beans and pulses.

3

Choose lower fat versions of milk and dairy foods.

0-4

Cut down on sugary and fatty foods.

How many portions do you eat in a day?