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SAMS group present 'Keeping Healthy' report

Information we collected at an event for 80 adults with a learning disability living in Surrey

It was a day of fun to find out about your rights, health checks and health screening. We held workshops, played health bingo and had lots of stalls to visit.

We asked people who came to the day lots of questions so we could find out more about what support people are getting and what people need more help with.



The event was held on the 24th February 2012



This picture shows people working in one of the groups

SAMS group set up the event with support from VoiceAbility and worked in partnership with Macmillan Cancer Support, Surrey LINK and Surrey and Borders Partnership NHS Trust.



Surrey and Borders Partnership 
NHS Foundation Trust



Introduction

A group including those from S.A.M.S (Self Advocacy Mid Surrey) Active Voices Group supported by VoiceAbility, Macmillan Cancer Support, Surrey and Borders Partnership NHS Trust and The Surrey LINK, who were all concerned at the lack of readily available accessible information, around cancer screening and keeping healthy, found they had a common purpose. The Surrey LINK were also looking at the use of Health Action Plans and the availability of GP Annual Health Checks.

We know that in Surrey (part of Surrey, West Sussex and Hampshire Cancer Network) 5,443 people are diagnosed with cancer each year and 2,682 die due to cancer each year (data from National Cancer Intelligence Network).



“Few people appeared to know about the range of services available from Macmillan for people with cancer and their carers.”

Quote from Macmillan professional

Surrey also has the highest concentration of people with learning disabilities in all of Europe and the joint vision between the partnering organisations lead to this event. We were also aware that people with Learning Disabilities were often unaware of their rights, and support being offered to them about various screening procedures.

Who was invited and who attended?

Invitations were sent out by VoiceAbility to many residential homes, supported living homes and Day Centres across Surrey. It was advertised on the Learning Disability Partnership Board website.

Surrey LINK invited commissioners from SCC, NHS Surrey, learning disability leads in the Clinical Commissioning Groups and the Learning Disabilities Associate Director from SABP NHS Trust to attend.

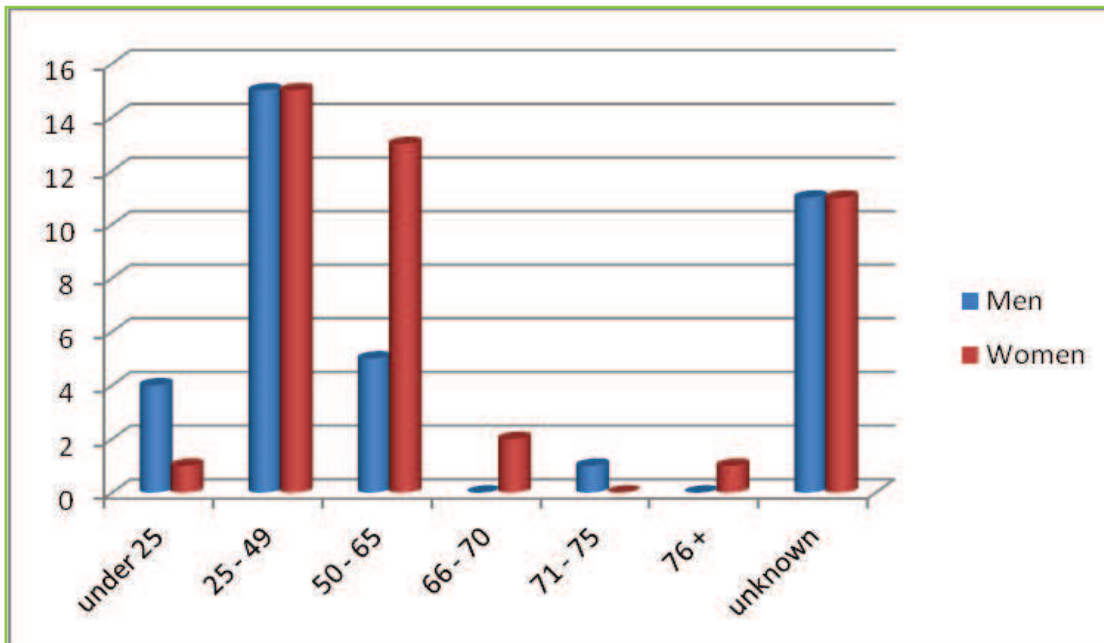
We paid RAD to attend to make sure that people with a hearing impairment could be supported to learn about staying healthy.

We asked Redhill YMCA to come and play Boccia, at lunchtime.

People came from Epsom, Ewell, Bookham, Ashted, Dorking, Horley, Farnham, Cranleigh, Guilford and Croydon.

“We got lots of people to play boccia, good game. It’s like bowling...we got and lots of people played.”

Graph showing the ages of people who attended



The age ranges for this question were based on the ages that screening is available. 36 men and 43 women answered this question. As this graph demonstrates, of these 79 people, 22 did not know how old they were. Given the aging population of adults with a learning disability in Surrey, we were surprised that more older people were not supported to attend this event.

On the day



We decided meet over a healthy lunch and to give time for people to meet up with friends. We paid the Firestone Rock Band to play to improve the ambiance on the day. Food was provided by Colebrook Day Centre where a group of people with learning disabilities have food hygiene certificates and use the money they earn to fund their centre.

“We talked about healthy eating and what food is healthy....fruit and apples”

Picture:

The Firestone Rock Band were fabulous and lots of people got up to dance

Quote from SAMS member

“The band was good, excellent, nice music, great atmosphere”

Quote from attendee

We had lots of stands that gave people information and asked them questions. To make sure people went to all the stands, everyone was given a 'Bingo' card where they could pick up a sticker from each stand. The Bingo card could then be swapped for a goody bag.

“I had my blood pressure checked and it was fine, they put a band on my arm and it was comfortable.”

Quote from attendee



Picture: Surrey LINK information stand

Things that we talked about include:

- Surrey LINK where people were to be asked if they'd had an Annual GP Health Check,
- Healthy Eating,
- Smoking,
- Health Action Plans and Hospital Passports,
- Bowel Screening,
- Blood pressure checks,
- Carers,
- Awareness and experience of cancer
- gender and age range of the attendees.

“The health bingo was good fun and I learnt things at the Macmillan stalls”

Quote from attendee

Goody bags with accessible information e.g. Annual GP health checks; healthy eating and cleaning teeth were also suggested by Macmillan Cancer Support so that people had something to talk about when they got home.

“Not everyone has an annual health check, everyone with a disability should be offered one, doesn't mean they have to take it.”

Quote from SAMS member

The Workshops

Two Workshops were run at the same time, and both workshops were run twice so the groups could be kept small. People were able to choose whether or not to go to the workshops, and most people chose to attend.

“The workshops were very good; we talked about cancer and self checking.”

Quote from attendee

The men’s group



One workshop was for men and talked about common cancers in men, including testicular and prostate cancer. In the group people were told about signs and symptoms, and a model was passed around so people could find out what they should look out for. The group talked about reducing the risk and staying healthy. Everyone was reminded to speak to someone and go to their GP if they have any worries. This group was run by the Macmillan Cancer Support Mobile Information Team.

“Having only had 3 patients with a learning disability, the day was a great experience for me.”

Quote from Macmillan Nurse

Feedback from the men’s group

- The majority of the men participating appeared to be unaware of self checks.
- They were challenged to feel for a lump in a pair of plastic model testicles.
- Some men returned to the Smoking stand afterwards and exclaimed that they now knew what he was talking about.
- When healthy eating was mentioned some of the men burrowed into their goody bags and brought out their healthy eating leaflets.
- There were fewer support workers required in these groups.
- People who attended the group were really keen to learn and some people talked about family who had died from cancer.
- Overall the men’s group seemed comfortable talking about cancer and keen to learn about signs and symptoms and risk factors.
- A support worker signed for their client and also a representative from RAD who signed for the benefit of the whole group.

The women's group

One workshop was run for women, and talked about breast and cervical cancer and screening. In the group people were told about signs and symptoms to look out for, and a model was passed around so people could find out what they should look out for. The women were told about their right to screening, as well as how to stay healthy and reduce their risk of becoming ill. Everyone was reminded to speak to someone and go to their GP if they have any worries. The group was run by the Learning Disability Liaison nurse from Surrey and Borders Partnership NHS Foundation Trust, and a Macmillan Breast Cancer Clinical Nurse Specialist from East Surrey Hospital.

“The smaller groups were more effective for people with higher communication needs”

Quote from Learning Disability Liaison Nurse

Feedback from the women's group

- Many of the women commented that they had been given smear tests.
- Some attendees including their supporters were not aware of the age threshold for mammograms.
- The first group required greater one to one support with communication and understanding. But it was hoped that support workers would take the message with them.
- There was more discussion with the second group as they required less support.
- The fake lumpy breasts were a good tool to interact with the attendees.
- The nurse showing how you should feel your breast was well received.
- It was felt that this message was more relevant than time spent on diagnosis, treatment and prognosis.
- The second group was attended by a support worker who had been diagnosed and treated for cervical cancer and talked about her experience, and this really engaged the group.

“Support workers appeared to learn a great deal from the sessions including requesting packs on ‘quitting smoking’.”

Quote from professional running workshop

Information we collected

50 percent of people we asked had a hospital passport, and 50 percent did not have one

65 percent of people we asked didn't have a Health Action Plan

14 percent of people we asked told us they know someone who has had cancer

65 percent of people had an annual health check in the last year. 35 percent of people we asked hadn't had an annual health check in the last year.

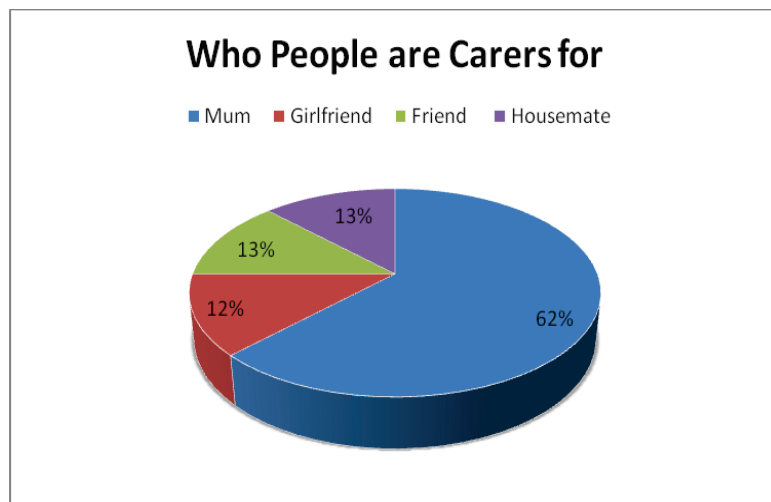
86 percent of people told us they had been to their GP in the last year.

Only one person told us they smoked and we gave them some information. Lots of support workers wanted help with this too.

We asked people who were the right age for **bowel screening** if they had received a pack through the post. 10 percent said yes. 14 percent said no. **75 percent didn't know**. This is very new but it looks like more work need to be done here.

17 percent of people we asked told us they are a carer

Of these 17 percent, people told us they care for:



Summary of Findings

- This was a very good experience and example of partnership working between health, statutory, charity workers and volunteers.
- There was a reasonable take-up on annual GP health checks and Hospital Passports.
- Quite a few people did not appear to understand what an annual health check was.
- Fewer people in Supported Living accommodation had a Health Action Plan.
- Support workers reported that they had learnt a lot about health screening – for example age ranges, and that some tests have to be requested. We hope this will have a beneficial impact for their clients in the future.
- The models used as tools in the workshops were very useful.
- It was interesting to note the number of people with a learning disability attending who regarded themselves as carers to their Mothers or friends or girlfriend.
- Having someone with a history of cancer within the group who shared their experience was very positive and helpful for group members.
- There was evidence of learning having taken place at this event, for people with a learning disability, support workers, carers and professionals.
- Some of the men talked without prompting in the group about the risks of smoking and also knew a lot about healthy eating. We know that locally around 19.2% of the population are smokers although this is slightly lower than the UK average (from Association of Public Health Observatories 2011).
- Some clients were unaware of their own age.
- We had a poster on the Macmillan Cancer Support stand where people were invited to express their experience of family and friends who had had cancer. It was very poignant as at least 14% who engaged with the nurse knew someone.
- 75% of people who were eligible for bowel screening did not know about it.
- Blood pressure checks were offered by a Community Learning Disability Nurse. Three people needed to be referred to their GP for follow up, this was discussed with the people affected and their support workers.

Recommendations

We make the following recommendations to ensure that the learning from this event is sustained and leads to improved understanding, care and access to services for people with learning disabilities in Surrey. We think that these recommendations are likely to be relevant and of interest outside Surrey as well.

1. Ongoing work is needed to support people with a learning disability in Surrey, as many areas of unmet need were identified through this event.

Macmillan Cancer Support, LD Liaison Nurse, CTPLD and members of SAMS Group will be meeting in next two months to discuss how this need could be met. We hope the outcome to be a service or new ways of working and /or a change in processes.

We recognise that scoping work may need to be undertaken as a group to inform future decisions.

2. The above group link with the Independent Mental Capacity Advocate (IMCA) service to provide cancer awareness training, share findings of this report and share best practice in supporting adults with a learning disability.
3. The majority of people who attended this event said they did not self check, and needed support and information on how to do this and what to look for. We thus recommend that people are supported to self check and that when people need support to do this, staff make appropriate appointments with health professionals to enable this to happen.
4. CTPLD Teams are supported by Macmillan Cancer Support to run groups to provide cancer awareness training for people with a learning disabilities.
5. Support workers are given training and information about how to support people to access screening and to self check.
6. Macmillan professionals (including nurses, information managers, and benefits advisors) have access to training on how to support adults with a learning disability. The Surrey LD Liaison Nurse has agreed to support this and the offer will be developed locally.
7. The LD Liaison Nurse is supported to run a workshop at the national conference for Macmillan professionals to share good practises with other geographical areas.
8. SAMS group, or other groups supporting adults with a learning disability, take part in developing and delivering the training.
9. Education / awareness sessions are run in schools, colleges and adult learning facilities for people with a learning disability.

10. High number of carers (17%) were identified at this event, many of whom we believe were not known to services and do not have access to relevant and appropriate support.

We recommend that further work needs to be done to look into this need, and awareness needs to be raised with community teams, benefits advisors and carers support teams, for the need for carers assessments.

11. Macmillan provide more information to diverse groups about the range of services available, as many of the people attended this event were not aware of the range of services offered by Macmillan Support services.

12. There is a need to ensure that checks and results feed into people's Health Action Plans which are regularly and appropriately updated.

13. The Surrey LINK LD Group will promote this work to Clinical Commissioning Groups and Healthcare providers over the coming months, and ensure that the work is carried into Healthwatch and the Health and Wellbeing Boards.

14. This report is shared within teams and organisations that supported the event to see what learning it is possible to implement.

15. This report and information gathered is shared with other partners, including information on how to hold a similar event.



“The day was a success people said they had a good day...super”

Quote from attendee

Resources

Macmillan Cancer Support Line

Emotional support

Financial support

Information and signposting to local services

Translators, text phone and email available.



<http://www.macmillan.org.uk/HowWeCanHelp/TalkToUs/Talktous.aspx>

Macmillan publications

Macmillan develops publications specifically for people with cancer, their family and friends. To see our full range of publications and order them free of charge, please visit Be.Macmillan (you will need to register to browse and order from the website) or call 0800 500 800.

<http://be.macmillan.org.uk/be/default.aspx>



Cancer Information and Support Centres

Our centres offer free, confidential information and support to everyone. If you or a loved one has been diagnosed, or you're worried about cancer, one of our team can help.

Find your local centre here:

<http://www.macmillan.org.uk/HowWeCanHelp/LocalInformationCentres/MacmillanInfoCentres.aspx>



Grants

For more information on the grants that funded this event, or to find out how to apply, please see:

<http://www.macmillan.org.uk/Aboutus/WhatWeDo/Inclusion/InclusionProgramme/InclusionGrants.aspx>

or contact your local Macmillan Involvement Coordinator for more information.

Contacts

The groups and individuals who took part in this event have shared their contact details in support of future events that may take place in other areas.

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