

1,000 Lives

Southwark stories informing the Health & Wellbeing Strategy and Health & Wellbeing Board

Southwark Health and Wellbeing Board
Public engagement 2014

Acknowledgements

This compendium is a selection of the personal and powerful stories told by Southwark people. Every one is sincerely thanked for sharing their unique contribution which will shape how we improve health and wellbeing in Southwark.

1,000 Lives

Our vision for Health and Wellbeing in Southwark

“Every child, family and adult has improved health and wellbeing and has access to high quality local services that meet their needs. Together we will invest to make a difference earlier in the lives of local residents, promoting resilience and self-management of health and giving everyone the best and fairest start. Working together to build a healthier future, we will tackle the root causes of ill health and inequality.”

Our vision is informed by the stories you told us about your health and wellbeing. With the help of Healthwatch Southwark, Southwark Council, the CCG and NHS Trusts and local groups supported by local volunteers and professionals, we heard from hundreds of people across Southwark. Stories have been collected from Southwark residents young and old, giving us an insight into the ordinary and extraordinary lives of the people of this borough. The stories were collected from public events, shopping centres, schools, libraries, day centres, children’s centres, voluntary and community groups, churches, leisure centres, GP surgeries and clinics.

The stories presented in the following pages are just a few of the many you shared with us. These stories reflect the diverse needs and experiences of our communities, from staying fit and active, to preventing isolation, to dealing with long term conditions, disabilities and mental illness.¹

Everyone’s story is different and what people felt helped them varied depending on their individual circumstances. However, there were some common themes.

- **Feeling connected** Positive relationships, the support of friends, family, community groups and volunteers were cited by many as integral to their wellbeing and their recovery from health problems. Problems in relationships, family breakdown and bereavement were often talked about as a cause of stress and sometimes a trigger for physical and mental illness. Loneliness and isolation featured in many people’s stories and conversely, many people talked about the strength they drew from a supportive social network.

¹ Some of the stories were written by the individuals themselves and others were told to volunteers who wrote them down, so not all the excerpts used in this document are direct quotes.

- **Confidence and coping skills** Some stories highlighted a person's confidence and a sense of being in control of their own wellbeing and optimism about the future. There were many stories from people who were born outside Southwark and the challenges they have faced. Levels of personal resilience had an impact on how people felt about the experiences they described. Some people who talked about suffering traumatic events or being the victim of violence, for example, said that they had struggled to cope.
- **Feeling the squeeze** There were stories highlighting the impact of the current economic climate on everyday lives. Poverty, unemployment and poor housing featured in many of the stories and had a negative impact on health.
- **Living with poor health** Many people described living with chronic poor health and with multiple health problems. People with poor physical health problems also described poor mental health and wellbeing – there being no health without mental health.
- **Valuing local services & praising local professionals** Many people had high praise for public, community and voluntary sector services and the dedicated professionals who had helped them through a period of illness or supported them in their daily life.
- **Valuing support for staying healthy** There was an appetite for more information on how to stay healthy and people valued, for example, health and other professionals talking to them about being active, being healthy and referring them to the right activities. People also valued the local facilities to support them to stay healthy, from the local parks, libraries to leisure services.
- **Access** Some stories described access to services, describing the potential for simplifying access and improving on signposting.
- **Caring & family support** There were stories from people who are carers for their children, partners, parents or other family members. Carers also talked about the impact of their caring responsibilities on their own wellbeing. The important roles that families and friends played in keeping them well featured in stories.

The 1,000 Lives stories reinforce what our JSNA (www.southwark.gov.uk/jsna) is telling us. Local people have shared their experiences to help inform the development of the health and wellbeing strategy and the priorities for the Health and Wellbeing Board. The health and wellbeing strategy will reduce health inequalities, improve outcomes for local people and support integration by:

- ① Giving every child and young person the **best start** in life
- ② Addressing the **wider socio economic determinants of health** which we know determine our life chances: we will maximise opportunities for economic wellbeing, development, jobs & apprenticeships, and make homes warm, dry and safe
- ③ Preventing ill health by promoting and supporting **positive lifestyle changes** & responsibility for own health (tobacco control and smoking, healthy weight, physical activity, alcohol, sexual health & HIV) and improving people's wellbeing, resilience & connectedness
- ④ Helping people with existing long term health conditions to remain healthier and live longer lives by **improving detection & management** of health conditions including self management & support
- ⑤ **Tackling neglect & vulnerabilities** by supporting vulnerable children and young people and ensuring positive transition, ensuring choice and control for people with disabilities and supporting independent living for older people in an age friendly borough
- ⑥ Supporting integration for better health & wellbeing outcomes by **integrating health and social care** that is personalised & coordinated in collaboration with individuals, carers & families and by shifting away from over reliance on acute care towards primary care & self care.

Improving health in Southwark

THIS IS HOW WE'LL DO IT

● Tackling neglect & vulnerabilities

Support vulnerable children & young people & ensure positive transition to adulthood

Ensure choice & personalisation for people with disabilities

Independent living for older people in an age friendly borough

● Best start

Ensure best possible start to life for children, young people & families

● Prevention

Promote positive lifestyle changes & responsibility for own health: tobacco control & smoking; healthy weight; physical activity, alcohol, sexual health & HIV

Improve people's wellbeing, resilience & connectedness

● Wider socio-economic determinants

Maximise opportunities for economic wellbeing, development, jobs & apprenticeships

Make homes safe, warm & dry

● Integration for better health & wellbeing outcomes

A more joined up service that is personalised

Shift away from over reliance on acute care towards primary care & self care

● Long term health conditions

Improve detection & management of common health conditions including self management & support

Giving every child and young person the best start in life

All children need a good start in life – from antenatal care to early years to when they start school and through their teenage years, giving them a strong foundation for a happy and successful adult life. Mothers contributed stories about the importance of good advice through pregnancy, choice and control of their own childbirth experience, support with breastfeeding and ongoing support through their child's early years. This section also includes stories about post-natal depression and stories from parents whose children have health problems, meaning that they need help from a range of services. There was special praise for our midwives, health visitors and our children centre workers. But there was also a desire to receive clearer, more consistent information. We were reminded of the essential role families play in providing support and the importance of enhancing community based support from professionals and voluntary and community groups especially for people who are isolated, vulnerable and without close relatives.

Young people's own stories focus on their desire to be active and healthy, building their self esteem and helping them to become confident and resilient young adults. The impact of bullying on wellbeing and the responsibility of being a young carer were mentioned by several young people. Young people particularly valued leisure services, swimming and gyms and organized activities such as football clubs.

Pregnancy and early years

- **“I went to the GP early in pregnancy.** In the end I chose a caesarian section because my baby was two weeks overdue. My midwife was very supportive. I was also introduced to the family service. An outreach worker gave me advice where to meet other parents and share good times.”
- **“I wanted a natural birth, but I was two weeks overdue and they hadn't induced me.** But I had very positive midwives who, despite me feeling fearful, kept to my wishes we'd previously talked about, keeping my birth natural. They motivated and encouraged me and helped me give birth safely. I have a very positive memory of my son's birth due to their support. Fabulous midwives”
- **“When I gave birth I felt isolated.** I didn't know anyone. At my six week check, the GP gave me a list of all sorts of services. I attended the Stay and Play at a medical centre in Bermondsey. The staff were really helpful and I got to meet other women who have babies and can make friends. And the nutritionist gave me lots of tips about food and weaning”.

- **“I visited the breastfeeding café before I had my baby.** I was glad I did because I struggled to breastfeed at first. The midwives kept changing their message about feeding and I kept feeling like a failure. The breastfeeding café made me realise I was normal, that the difficulty initially was normal and helped me to feel better”.
- **“I’m on maternity leave** after giving birth. My pregnancy was fine up until the birth of my daughter. The labour was very slow and painful and I had to have a blood transfusion due to losing a lot of blood. The midwife who was mainly looking after me wasn’t very sympathetic and I felt patronised by her. I also struggled to breastfeed and apart from a couple of sessions with the midwife to show me how to do it, I was pretty much left to my own devices.”
- **“The Outreach worker at the Children’s Centre’ made the biggest difference to me.** I was 17 when I had my first child. I was scared, but wanted a good future for my children; I wanted to set a good example but did not want them brought up on benefits. When I had my first child I could not find services, I did not know where to go for help. It was very hard to find information.”
- **“I am a new mum.** I feel mostly good and had good services but had a bad-ish experience. My GP told me my son was overweight. I thought that was odd as I’m big and my husband is tall. I was told to feed him less. Then I saw the nurse. She measured his height, and said his weight was OK for his height! I was a little angry with the GP about this.”
- **“I got pregnant last year** – it wasn’t planned but it was with my long term partner, so we were really happy. I went to my GP and he referred me to the hospital where I started to have regular visits and scans. I wasn’t given any choice of where I could go but I was happy with the services I was referred to. The people that were involved in my pregnancy was my partner obviously, and the GP, the midwife, the health visitor and my sister – who was really good at cooking food for me when I really didn’t want to! I felt like I got all the help I needed – I was given the information I needed as this was my first pregnancy. I am really happy within myself and I have always wanted to be a mum so I am quite pleased. I feel complete – she has taken over our lives.”

Parent experiences and support needs

- **“After giving birth to my first child, I had post-natal depression.** The doctor gave me sleeping pills, but it didn’t help. I self-referred to the Maudsley and now I am in recovery and hoping to move on. During my second pregnancy I asked for help from the mental health services team and asked social services to help, but they

said no. If things had got worse they would have come but I was trying to avoid that. Southwark Reach were helping me. I was referred to Building Bridges, then Newpin. You can only use Newpin for two years, but there's no where else like it. "

- **"When I had my child two years ago I discovered after having her I felt low all the time.** My husband sorted a doctor's appointment for me and I was diagnosed with post natal depression and started to take anti-depressants. I was scared at first – about feeling numb or having no feelings – but it was the best decision I had made for myself and my family. My doctor also referred me to a mother and baby group, it was a course for 12 weeks and we would discuss our individual coping methods and give each other support and ideas about motherhood. The Health Visitors who ran the group were brilliant. I didn't feel judged by anyone and I didn't feel like I was an alien for feeling the way I felt. I became stronger in myself with time and I recovered. Soon I couldn't get enough of my baby. The group I attended was literally life changing for me and because of them I am a happier person and a stronger Mum".
- **"Before I was introduced to SureStart Aylesbury I felt isolated and lost.** They helped me be a part of the community, gain confidence and be a confident parent. I made friends which I still have, we helped each other and meet all the time. I don't have my family in this country so having good friends are very important for me and my children."
- **"English is not my first language.** I have got support from ESOL classes at Kintore Way. I found out about them in the play group. My health visitor told me about the play group. I have made friends in the play group which is good for me learning English. When I had just had my baby, I got a bit depressed, but the play group helped with that."
- **"I look after my 2 year old son and live in Southwark.** I was in a difficult and abusive relationship. I had many miscarriages. I learnt to accept help. The mother and baby unit helped a lot with practice needs ensuring I take my medication. Therapy through the NHS helped but I had to wait until I got worse, when I was really bad before I got serious help. My Homestart volunteer helps and we will be friends forever. She showed me love and was even there when I was in hospital. "
- **"The Outreach worker at the Children's Centre' made the biggest difference to me.** I was 17 when I had my first child. I was scared, but wanted a good future for my children; I wanted to set a good example but did not want them brought up on benefits. When I had my first child I could not find services, I did not know where to go for help. It was very hard to find information."
- **"Surestart parent course changed my life.** Now I am almost where I want to be which is training as a childcare officer and doing my placement."

- **“I tried seven colleges but there were no crèche places for my son and my English was also a problem.** I finally found a college with a space and I have been learning English. Colleges don’t always advise us where to find optional childcare provision. My son’s school is very good they are teaching him to speak English and he teaches me. The NHS and school have been very good. People in my community now realise it is very important to learn English because the council does not provide interpreters anymore. English classes are sometimes provided in the evening which is not ideal for parents. It is better to provide English classes during the day in term time. I am good at mathematics and next year I hope to study mathematics to get a job in a bank.”
- **“You will see the light of the tunnel in the end.** I was low my partner had been violent and I was in shock as my son’s father was in prison. During the violence I called the police and social services, but social services could not help anymore. I referred myself to Homestart. The Homestart worker was lovely and a nice person. They helped me with forms and advice. Sometimes I would just cry and talk – they listened and told me I was OK and would come through. I was a good mum to my son. Now I want to support people the way I was supported.”
- **“I was struggling to get my life in order.** I had two children, I was a single parent and I had no family to help me. I got help from Southwark Reach and the personal advisor helped me to set goals. I also had a family support worker who helped me to secure accommodation and make sure I paid my bills on time. She helped me secure a nursery for my son when I wanted to go back to college. When I wanted to start university my family support worker helped me to secure a place in an after school club. The staff at the after school club have helped me a lot and I don’t know what I would do if they ever closed down. I am now nearly finished my final year of university.”

Parents and carers whose children have health problems

- **“My second child was diagnosed as autistic and it was a total shock.** My depression got worse because I didn’t know anything about it. Although I got information about it, the fear grew in me about my son’s future and how it would affect my family. My worker at Sunshine has been the only person I know I can get in touch with if I have a question about my son’s situation. But I am not happy because I think that there should be more support for parents. Contact a Family is a good support. Southwark Carers as well. But I am feeling isolated. I barely know another family in my same situation. I strongly suggest that Southwark should be giving more support to children with special needs, especially autism. Play groups, workshops, story groups etc. I don’t have a place I can take my son where he can understand, with no problems because of his condition, with no judgments from others.”

- **“I am the mother of a child with a chronic health condition** – a rare one, that took 18 months to diagnose. Since the diagnosis my daughter has been taking a ‘special’ order prescription with a short shelf life, which has meant timing her script requests and orders to the day almost. Sometimes the GP has failed to understand this and occasional delays have caused us to panic. A point we parent carers often make is that GPs are not the best people to talk to about or sick and disabled children; consultants generally are. Four years ago, my children’s dad and I separated. He has recently been diagnosed with heart failure and diabetes type 2 which has left him very depressed. As for me, I am reasonably healthy but am due to have surgery for a benign tumour. We are reliant on another single parent to look after the kids whilst I’m in hospital. My hopes and aspirations for the future are that health, education and social care worked together more closely to offer seamless services of choice and that they communicate more effectively to reduce the need to repeat our story.”
- **“My son when he was two was diagnosed with cognitive communication difficulties.** We are at the stage of waiting for school speech and language therapist to pick it up. He is four now. Health services are quite good. Although there is a gap between Early Years and school picking it up. The school has made the biggest difference.”
- **“I take my eldest son to regular visits to the eye specialist.** The hospital has generally been good, but they lost his records twice. We keep having different consultants so we had to explain over and over again. The GP speaks in plain English, but eye specialists did not. My son’s glasses have to be changed every 3 months - he doesn’t like being teased. I would advise that people take a pad and pen when they go to the GP and consultants and write down notes.”
- **“I have no life of my own I am living only for her.** My baby niece has had HIV since birth. It’s very traumatic and I have ups and downs. The hospital and local doctors are very good services. No one knows about my niece and this affects me as her carer. Somehow we have managed and things are OK. I don’t have transport facilities to take her about to appointments etc. It would help a lot to get a bus pass.”

Children and young people and their own health and wellbeing

- **“I couldn’t afford to go to the gym because I had no money, so I was down.** I ate out of boredom. I would often come downstairs at 3am to eat snacks. My mum supported me when I was in secondary school. I did not enjoy PE because I don’t think I was encouraged to do it enough. No one gave me a kick in the bum. I felt depressed at that time and thought I had bipolar condition. I did have a school counsellor which helped. I was naughty and was kicked out of school for a month. I

also messed up my exams. My doctor told me I'm obese. The thing that made the biggest difference was mum taking me to the gym. Mum and dad separated but I would have liked to have seen more of my dad to support me. My hopes and aspirations for the future are joining the army and keep going to the gym and swimming."

- **"I'm 15. I smoke cigs.** I've been chased by the police because of friends. I've stolen from shops. I would advice someone at the beginning of my journey to find the right friends to be around."
- **"I was the only person from my primary school to start at my secondary.** No one heard me speak in Year 7 because I was so shy. The reason why I was really shy was because I was being bullied. They would take the mick out of me in all my lessons. So I had no self confidence or confidence in general. After a while I found someone who was just like me and we are best friends and we have made more friends."
- **When I was in Africa I was healthy.** I did running there and when I came to England in 2012 and I waited a while to start school. When I did start I had to learn English. I would ask the teacher when I didn't understand something. My mum took me to the doctor when I needed it because I couldn't speak English and she would translate."
- **"I'm a young people who is homeless,** I suffer more now with my health than I did before I became homeless. Being homeless brings a lot of health issues and there is not enough support for a lot of these types of things. I'm still good spirited, but I do feel frustrated and upset that not more is done to help young people like me."
- **"My mum has always had epilepsy.** I'm 10 years old at the moment. I was at home in my room and I just knew that my mum was having a fit. I put her on her side and called 999. They checked if she was OK and she stayed at home. My mum has told me how I should take care of her. I've practiced all the things to do if I find her having a seizure."
- **"We were playing football** and a boy kicked the ball at my stomach and I fell into a ditch. I broke my arm. I was taken to A&E at Kings College Hospital and was given a cast on my arm. I was taken in an ambulance there. The nurses were great. The doctors talked to me as well."
- **"I am a 16 year old male.** I coach football for a local football club. I feel healthy – taking healthy exercise and winning every week. My mindset is to keep fit and I'm able to do that. I feel better about myself when I am doing lots of different activities. Seeing children being active is rewarding, especially when their confidence is very

high. With ten year olds who enjoy playing and learning new skills – it’s great to be helping them. I thought I was skinny and should eat more when younger. Felt low when I compared myself to somebody else but now I think differently – about what I’m good at and not how I might look like.”

- **“I am 13. I was born healthy and grew up in a clean house.** However I wasn’t able to speak until I was 7 because I have a bad lisp. But I knew how to use sign language. This helped me a lot to answer questions. I never got bullied because I had older brothers and a good family who looked after us”.

Building healthier and more resilient communities and tackling the root causes of ill health

Being active, feeling positive and having a healthy lifestyle can help prevent us getting ill, but not everyone in Southwark has the same opportunities. Some of the stories in this section describe how people's health has been affected by difficult times in their lives, by domestic violence, by losing a loved one, or following an accident or a crime.

Some respondents shared their experiences of changing their lives, with some moving away from unhealthy behaviour like smoking or abusing drugs and alcohol. Unhealthy weight was raised as a concern. Many people talked about the struggle to lose weight and to become more active, with some highlighting difficulties finding the right services that are affordable and accessible. The vast majority of those who said they did take part in sport, exercise and other activities agreed that taking part in social and physical activities made them feel more connected to the community, prevented feelings of isolation and increased their wellbeing.

Financial wellbeing, money worries, worklessness and the importance of 'good' employment were common themes underpinning many of our stories. Professionals and voluntary organisations as well as friends helping to sign post, navigate and refer to relevant services were especially appreciated. The importance of everyday physical activity as well as affordable leisure services for all, including some specialist services, were highlighted.

Difficult circumstances and health and wellbeing

- **“My story began about ten years ago when I migrated to the UK.** Life was quite difficult as an illegal immigrant. I had no job, I was squatting and did not get or seek information. I got pregnant and had my first child as a result of prostitution. When I had my baby, the health worker was really of help and gave me loads of information. I had no self esteem, I was depressed and poor. It was a struggle. I opened up to my health worker who advised me to seek legal help. My lawyer applied to the Home Office and I eventually got my stay. I am getting ready to get a degree at university. I want to become a nurse.”
- **“Depression began in my early 30s.** Arthritis at the same time. I had an unhappy childhood and marriage leading to divorce age 40. I lost my only son to cancer in 2002. I was estranged from dad after he left my mum and estranged from siblings along the way and I've had problems with my daughters. I've had medication for arthritis and depression for many years. I'm very lonely, but I go out to be around people.”

- **“I work as a waiter and I have been having really bad toothache and really bad black liquid coming out of my gums.** I’m not registered with a dentist or GP. I tried to access the emergency dentist, but I had to go back to work before seeing anyone. I have to work very long hours in a restaurant because it’s expensive to live in this borough”.

- **“I had long term substance misuse and I was in an abusive relationship.** My two eldest children are with a foster carer, but I have regular contact. I also have a younger child who is on a supervision order. I was referred to Newpin by my social worker. Newpin helped me know other people that had similar problems. I stopped using. I have been able to make friends from Newpin who we see outside the centre. This has helped me and my son feels more confident and able to lead a normal healthy lifestyle.”

- **“After the birth of my second son I had high blood pressure** and went to my doctor who put me on high blood pressure medication. I don’t smoke and I take care of my diet and I walk a lot. I still feel unwell and need help. Stress is a problem. I am a single parent, I have 2 children and I have moved. No one can help me. I moved to get a change. I was being harassed by my ex-partner. Now I am safe but lonely. I would like my children to be safe and my health to improve.”

- **“I am from Nigeria.** My children and I are in a better place now. My husband left me because he impregnated another lady. My husband was abusive to me and my children and he was always shouting and violent. I was very shy, not confident and could not express myself. I used to cry a lot which really affected my children. My friend recommended I go for counselling with my children, which really helped me.”

- **“About three years ago, my husband left me and our daughter.** Since then, it has been a struggle. I got really depressed, as coping bringing a child by myself and working at the same time is so difficult. The money issue is always there – after paying my bills, rent and travel I’m left with £150 to survive until next pay. It puts enormous strain on me as I want all the best for my child. At the moment I’m getting counselling at my GP’s surgery and it’s really great to have someone to listen. As well, I’ve been referred to the exercise programme. I got a bit stronger and it was great interaction, but I wasn’t able to attend as often as I wished because of money. Today I had my three month review and I didn’t even notice, but apparently, my outlook to the world changed a lot, in three months exercising. I started to feel more open, more positive about the future and even more relaxed. I won’t be going to the gym now, but I asked the instructor for advice and she told me lots of ways to keep going at home. Talking with people helped, but what really surprised me was that becoming more physically active changed me so much. And I even lost some weight and inches from my waist! The thing that made the biggest difference was going out of the house, interacting with others and getting distracted, even for a short time, forgetting about my problems. My hopes and aspirations for the future are for my

financial situation to improve so I can provide for my daughter. If someone was at the beginning of my experience, my advice would be to seek help – don't suffer in silence.”

- **“I’m a recovering alcoholic, but have stress related binges sometimes.** Fifteen years ago I was a domestic violence victim. My child’s father assaulted me several times and I was depressed with my life. I began to have anxiety and nightmares. I got married to a man that I met, but we are now going through a separation after ten years. I have a very good job which I have been with for about 20 years – I enjoy it very much.”
- **“I had a car accident and had some injuries and whiplash.** Where I live was not helping the situation and I turned down a few properties that were offered to me and I think that was a bad choice. The hospital has been excellent. I’m slowly recovering but I cannot work fully. Every day is a challenge healthwise.”
- **“My friend died of cancer two years ago.** After she died, my car was clamped just before her funeral so I was unable to go – this depressed me very badly. I was grieving for two years, but did not understand these feelings, so it developed into depression.”
- **“I came to this country, I had no family and felt very alone.** A family friend had brought me here and was sexually abusing me since the age of 17. But I spoke to the college I was attending and they helped me and got me counselling. Then I met my partner and we now have 3 children. I joined Newpin as per advice from my psychologist which is helping my children play nicely together and with other children. I was finding it a problem coping. My GP was helpful when I was pregnant she referred me to a social worker for 6 months because of my mental health problems.”
- **“I was lucky to have Homestart.** I became ill after I lost my twins, I started avoiding my friends and felt that people were laughing at me. I had immigration problems and they stopped me from working - that depressed me even more. My doctor prescribed me antidepressants, which I took regularly. I was hearing voices and felt I was worthless. I had no family in this country and my relationship broke down with my baby’s father. I got help from Homestart before my son was born, then registered at Newpin. I became happy, I socialise with friends. I still at times get agitated and panic but I have built up confidence in looking after myself and my son better.”
- **“I became depressed about 18 years ago after the death of a very special little someone.** I was scared of everything. The sun did not shine so bright. I got counseling but it did not really help. I had panics attacks. No sleep, no dreams - how can you have hope if you don't have dreams? Then a few stars came along to help

me climb the ladder - they live in my heart. Love and support help and I've realised how much a good day means to me and how powerful it is."

Lifestyles and behaviour and taking positive steps to improve our own health

- **"I am at the beginning of my weight loss journey.** I am 40 years old and been trying for a baby for over five years. I've got polycystic ovary syndrome and my GP advised me that reducing my weight might increase my chances of conceiving. I was really apprehensive about going to the gym and starting to exercise, so my doctor referred me to an exercise programme, where I get more support, not just about exercise but about health living, diet and making small changes all the time. It is really helping me with my confidence."
- **"About ten years ago I had a bad chest.** I got a cold that went to my chest and that affected my breathing. I was a carpenter – the sawdust affected me. The nurse at Albion Street suggested doing exercise. If I don't exercise, my chest clogs up with phlegm. I've just had a grandson and I want to be there for him. What helped? My family, exercise, friends – a bit of banter does you good."
- **"I was in the cafe at St Thomas' when I had a heart attack,** 12 months ago. I'm suffering with SAD and depression and feel low when I'm on my own. Family and friends, exercise class and being active helps. I manage my normal activities and look after someone as a volunteer. Having the heart attack changed my life. I'm trying to get back to full fitness and my hopes and aspirations are to get back to normality. If someone was at the beginning of my experience, my advice would be, 'Take it a day at a time. Don't rush things.'"
- **"My doctor advised me to take up exercise to improve health and wellbeing because I was overweight.** I don't feel different at all; I just feel if the local gym was more affordable, I would use it more frequently. It's cheaper only for people on benefits Why?"
- **"I don't have health problems, but do feel the necessity of taking care of myself** and that goes with instructive and nice pilates courses. Since I attend pilates courses I have less pain and apprehensions with my body and social relations at large."
- **"I used to work 12 hour shifts and came home to eat and sleep and discovered I couldn't.** I was tossing up and down and feeling tight in my chest. My wife thought it was heartburn and she was busy massaging my chest. Then it occurred to her that it was getting worse and it may be something else. She quickly dialed 999 and in ten

minutes the ambulance was at the door. They quickly examined me and lifted me into the ambulance and throughout the trip to Kings College they were attending to me and telling me what was happening to me – I was having a heart attack. When I was wheeled into the theatre I was a bit scared, whether I was going to make it or not – I was apprehensive. My daily life now consists of healthy eating, healthy living and exercise and I care about everything I do.”

- **“I’ve been smoking since I was young** – always smoked but never around my kids or grandkids. Smoking has been part of my coping, especially during the grieving process (I lost my husband).”
- **“I was married but used to use cocaine and heroin.** Because of my drug use I lost my family and was put in prison for theft. I was very violent and unstable. At points I felt like committing suicide. My daily life was messed up. My mum helped me. She tolerated me and would visit me in prison. A few of my friends directed me to the right services. When I went to prison I found out I could stop my habit. My hopes and aspirations for the future are to be totally clean and go back to school and have my chance to see my son.”
- **“I went for a health check and was told I was obese and that my health was at risk.** I was referred for another appointment and they talked me through my options. I decided to attend the Shape-Up programme and it has been great and really helped me to change my lifestyle. Sometimes I find it hard to attend the group, though, because I work long hours.”
- **“Right from when I came to London I had made up my mind that I would pursue a healthy lifestyle and this is what I’ve been doing.** I try to eat wisely, small portions of healthy home-made meals, fruits and vegetables and exercise. I feel great and on top of my world”.
- **“About 7 years ago I was in my mid 20s and felt really unfit** – I didn’t want to get fatter and fatter so I entered the London Triathlon as a challenge. Found a local triathlon club helped me to stay focused. Being fit and healthy makes me feel much better about myself and my mood is always much better after a run or a cycle. I work exercise into life – cycle to work, run home etc. otherwise I have no time.”
- **“I’m a stay at home busy mum with three children aged nine, seven and three.** I wanted to find some ‘me time’ and do an enjoyable exercise activity as well. I always liked the noise tap shoes make, but I never tried it until now. I love my tap dancing classes. I love the routines and making new friends.”

- **“I’m a pensioner.** I live at home and look after myself and my partner. I’m relatively healthy, but I had bronchitis recently and I was not informed whether I can get a flu jab. Can I?”
- **“I’m visually impaired.** I use ‘Wheels for Wellbeing’ to cycle every week and keep fit and healthy. My doctor told me about it. I love it. I come every week.”
- **“I’m a parent wanting to introduce fitness and healthy eating to my children.** I live near Burgess Park and there isn’t a Leisure Centre close by.”
- **“I went to the GP, who said that my blood pressure was getting high but did not really say much in the way of guidance.** This went on for a number of years until I changed to a lady doctor and she explained everything and said that my blood pressure was high and damaging my heart. I was referred to the gym and sent to have tests, as I felt my heart was not quite right. I had an ECG which showed a weakness. Then I had a scan which showed an enlarged heart, weak on the left side. My family was supportive and the GP was helpful, but mostly I found things out and did things myself. I was pleased with myself when the GP said I had lost a lot of weight and did well with exercising for an hour every day. Having to keep to a new lifestyle is difficult. I have lapsed into some bad habits again. Eating healthily is really difficult as it costs a lot of money to eat fresh vegetables etc. Also life does not allow time to prepare healthy food every day. My first GP could have explained all the long term effects of having high blood pressure. “
- **“I have problems with sleeping.** This has been going on for 15 years or more. I’ve tried everything – exercise, relaxation techniques and been to the GP, but I’m not keen on taking sleeping tablets. I’ve tried it, but it made me sick. I work part time now to have less stress. I notice as I’m getting older more and more health issues are appearing. Is that natural or not??”
- **“I moved to Southwark four years ago and haven’t needed to use the health services.** I keep healthy by using the Southwark swimming pools. The scheme that means students can swim for 60p with a Fusion card is great, as it makes keeping fit affordable and accessible.”
- **“I am 69 and am looking forward to playing cricket again in April.** Since I took early retirement in 1994, I have spent seven days a week doing voluntary work for various organisations. I last drank alcohol and smoked when I was 13. I have benefited in many ways from those decisions. I have a lot of fun every week in ordinary situations.”

Improving the experience and outcomes for our most vulnerable residents and enabling them to live more independent lives

Older people, people with health conditions and people with disabilities may require a range of services to help meet their health and wellbeing needs. People talked about the effect of long term conditions and the impact of multiple health conditions on their lives. Many stories featured a desire for more choice and control over what happens to them and others talked about health, social care and other services needing to work better together to provide a better service for the individual.

This section also includes stories from people who have been affected by mental illness. They talked about their experiences at times of crisis and the support they continue to need to stay well.

The stories especially emphasised the importance of local professionals, voluntary and community groups and carers for this group. Worries about ageing, bereavement and isolation were common themes.

People who need care and support to help them in their every day lives

- **“I find it hard to get about on my own - my carer helps me here;** I love it, I feel free and the exercise is good for my lungs and also for my mental health, it makes me feel better about things. My GP, hospital and family are all great, the only one I didn't like was when I saw a different doctor, he didn't really listen, it seemed like he was too busy. My physiotherapist pushed me but in the right way made me believe in myself. I'd love to work - get a job where I can help people like me move on and move around. Take every bit of help you can get, but in the end it's down to you to just do it!”
- **“I like coming to Bede House.** They showed me how to cook for myself – cakes and wholefood. I am helped to know how to shop and housekeep, it keeps me busy.”
- **“I had acid thrown into my eyes more than 20 years ago in a pub.** And I'm diabetic, too. Social services have looked after me and visited me. And they've helped me decide what sorts of help are relevant to me. It's hard. It felt like I was starting at stage one again. I feel like a bird whose wings have been clipped. When you've got a white stick, people look down on you and some people don't understand. But the carers visit me every day and help with my insulin. And I go to day centres and play games and meet other people.”

- **“I am 53 years old.** I am from Southwark. I do voluntary work and help out in the club and I come to Speaking Up. I have learning disabilities. Back in December I collapsed and fainted. I was taken to Guys and St Thomas Hospital. I had pain in my stomach and wasn't feeling well. I am well now. I feel lonely at the moment. I lost my partner last year. I go to counselling at Guys. I've been to six sessions where she helps me with breathing and relaxation. I have a key worker who helps me with a lot of stuff. I wish I had my partner back, but I can't do anything about that.”

- **“I had an accident and I'm paralysed** – over a year ago it happened. My wheelchair was nicked and I can't afford a new one.”

- **“I am a pensioner with ulcerated legs.** I need compression and steroid cream once a week. Booking GP appointments is not good. 10 minutes is not enough for a consultation. GPs are stressed and they're doing too much. And there aren't enough district nurses. And they need to share information. I'm constantly telling my story over and over again”

- **“The doctor could have given more information.** While waiting for the appointment at hospital I did not have much knowledge about what was going to happen at the appointment.”

- **“I'm a woman who's just turned 50 and am having a rotten 50th year.** I had operations to both hips to realign a defect and lack of at home service resulted in attending the hospital just to get the wound cleared. There was a lack of communication between Southwark Council and health services to provide information on my case. The nurses turned up without equipment. Doctors, nurses, consultants; some can't wait to get rid and cannot fully explain their reasons for increasing your medication. Since contracting epilepsy I've had very low self esteem and felt unable to cope, but family support was key. I'm now very anxious and stressed due to lack of understanding by my organisation. I need to help myself or continue on a downward spiral. Therapy to be undertaken soon which may raise my spirit. My hopes? That I grow old without the illness dragging me down.”

- **“I do not get any help for my wife.** We are 82. I would like to see more done to pensioners especially the older people.”

- **“I am a pensioner.** I use the gym, computing and pilates. I have type 2 diabetes. I have a cancer diagnosis but five different opinions and need to go out of borough. I don't mind dying but don't want pain. I was taking tablets / meds for diabetes but stopped. I also have osteoarthritis, but can't do anything. I need help on nutrition. Pills make me feel bad.”

- **“I am a disabled elderly person** who has just moved into Dulwich. I am exploring what is available and accessible for disabled people and above all else what people’s attitudes are to disability. I am an independent feisty lady who is determined to live life to the full and what is more, wants to improve conditions so that all disabled people can have the opportunity to do the same. I have great admiration for all those who put up with my many bad tempers. Those nurses who smiled, listened, doctors, consultants and physios; how would I have managed without them? I have been involved with disability organisations. We have made a lot of difference to disabled people’s lives. This work will never end until disabled people are treated as equal members of society.”

- **“I am full time carer for my wife who has had a stroke and now has dementia.** Sometimes I need help just at night or early (very early) in the morning and people won’t help at this time. Our children have moved away so no support from family. We have had 50 years of happy marriage, it’s only the last year where things have got difficult. My hobbies are fishing, which I have had to give up. There is not much support for me to know what I’m entitled to. I play chess on the computer when my wife goes to bed, now I have no one to play with. A neighbour told me about disabled living allowance. No one had told me about this before - why did it take a neighbour to tell me this?”

- **“I’m not disabled I’m differently abled.** I can do anything, in a different way.”

- **“I used to live with my mum and dad, but they died.** It was sad. Then I moved in here, over 30 years ago. A lot of people have died. A lot of people are still here as well. I did not like school. I don’t like going to the doctor. I take medication. I like knitting. I like going to the pub. I like to have a pint. I like eating fish and chips most. I like peeling the potatoes. I like going to my brother’s. I go on Sundays. I go for Christmas. I like doing what I am doing. I don’t want to change anything.”

- **“The day centre is great** – I come twice a week. They pick you up – there’s a hot cup of tea – toast and marmalade – I love it. I had a stroke in my sleep about two years ago and I worry about having another one. I’ve got carers who give me breakfast and get me ready. In the evening they microwave a meal for me. My daughter’s coming tonight – I managed to cook a chicken stew so she’ll be pleased. My daughter comes twice a week with shopping and pays the bills.”

- **“I don’t know when I came here.** The care worker says that I came two months ago but I can’t remember. I am in good health. I don’t like it here. Nothing to complain about but I miss my home. My family doesn’t visit me very often. I’d like to know when I’m going home – I don’t know what it’s costing me, you see.”

- **“Mum’s been taken off the dementia tablets, she’s fully disabled and bed bound.** I think Mum had many mini strokes. She fell off a bus, then began repeating herself, stopped going out and forgot she used to smoke. It has been so hard accessing services. I have been angry and cried rivers. Things could have been different if Mum had been diagnosed earlier.”

People with long term health problems or conditions, some with multiple concerns

- **“I am 67 and I have type 2 diabetes** and my blood pressure and cholesterol are controlled by drugs. I had one knee replacement. I think most of my problems stemmed from being seriously overweight from about the age of 30 onwards. When I was diagnosed with diabetes I decided to take it seriously and find out about the disease and the best ways of controlling it. I lost 3 stone, firstly with the medication and then being careful about the things I ate. I also had some difficulties with my lungs and I was diagnosed with sleep apnoea. I was put on medication, but when I lost the weight the symptoms disappeared and the doctor took me off the medication for sleep apnoea I have always found that whatever brand of the NHS I have dealt with, has been extraordinarily helpful. Doctors need to be honest and advise people to take their diabetes seriously. I have not allowed this condition to affect my life or slow me down and always say that ‘the problem with retirement is you can’t take a day off!’”
- **“I was the victim of a mugging and I was shot.** The bullet is still in my spine. My walking is not strong – I use a walking stick. I had a lot of help from the NHS with counsellors and other professionals. I go out socially when I can afford it. Friends and family help me. You have to be careful not to demotivate yourself. I was 17 stone, now I am 15. I am also diabetic and have high blood pressure after retiring. My ill health affects my movements and way of life. I can still get around and the diabetes and high blood pressure seem to be controlled. I used to drive but I can’t any longer. I come to the gym two or three times a week for sessions with a trainer and have reduced my weight, blood pressure and sugar levels. I would like to lose another stone at least.”
- **“Employers need to look past physical problems.** They are not insurmountable”.
- **“I first became seriously ill shortly after moving to London in my early 20s.** I found myself suffering from severe fatigue, barely able to keep myself awake in the late afternoon, despite going to bed around 9pm every evening. On top of that I started suffering severe bouts of insomnia as well as panic attacks that left me unwilling to undertake new activities and experience a proper social life. After almost two years of tests and examinations, I was put on medication to try and help and over the following few years my health started to improve as the doctors found the

appropriate levels of medication for me to take. Certainly, the high point was meeting my future wife, although I remember suffering a terrible panic attack on our first date and thinking I'd completely messed up the evening. She was the first person I confided in with regards to how I was feeling and what I'd been going through and it was actually an incredible feeling to be able to share that with someone and not to be shunned by them."

- **"I was diagnosed with diabetes at 35 I am now 65.** My GP is very helpful and encourages me to stay healthy and gives me hope".
- **"I am glad I got tested at the right time as a lot of people were dying at that time.** I was able to access the treatment and support services when I was diagnosed with HIV in 2001. I have been living with HIV for 13 years and still feel as fit as a fiddle. I have improved my health with the help of medication and I feel very healthy and fit probably compared to someone who does not know his/her status. I would like to be known as the one who has lived the longest with HIV positive."
- **"I have Asperger's syndrome.** I was born with it. Me and my mother were not getting along and I moved out. I started to follow my friends and made some good choices and some bad ones. I got my own flat, but I didn't like living by myself. I was lonely. It was hard. My mother took me to the GP and that's when I was diagnosed by mental health services with ADHD. Being diagnosed helped because I could understand why I was a certain way. If someone was at the beginning of my experience my advice would be to never miss out on an opportunity, follow your inner voice and try not to be distracted if you have a special need. There are services that can help you."

Dealing with mental health problems

- **"I was 17 when I had my first breakdown.** My mum had left home. She left my Dad with seven children when I was at boarding school. I was 14 at the time. My dad was amazing. He raised the whole family on his own. I have in and out of institutions all my life because of special needs and mental health issues. Until two months ago I was living in a shared house with a key worker. I always need reminding to take my medications and keep out of hospital."
- **"I lived on the streets for years** battling drugs. I didn't know why and I didn't know where to get help. I found out I have Post Traumatic Stress Disorder and personality disorders. Because I'm not dangerous I don't get any treatment. I'm not anti-social, I'm a-social. I'm predisposed to being a hermit. All I can do is use exercise to try and get better. It also gets me out of the house. It takes every bit of effort. I have to get

up and love swimming. In the past I would have had 6 months intensive treatment. Now I don't get anything – programmes have been reduced from 6 months down to 2, so they can't do deep work. I know what's wrong with me but it's hard to do what I need to without the support I need.”

- **“I am suffering from mental illness.** While at home I felt isolated as my flat was in disrepair very badly. I put my name down on the housing list in other areas. My cousin did a mutual exchange with me and I moved closer to my family. The new GP who I joined has helped a lot and I have cognitive behaviour therapy at the moment. I have better feelings about myself now. I'm not sure how I let my flat get to me. Therapy helped me to see that loads of things can sometimes get you down, but your home is where it starts. You must be comfortable. I hope to buy a house of my own – I'm working towards it.”
- **“I was diagnosed with chronic depression.** The mother of my children stopped me from seeing my kids for no reason at all. I had children at a young age and separated from their mother. We did not get along. I then stopped eating food. I didn't know what was wrong with me. The mental health services came to my home and took me to hospital. I then moved to another hospital for an assessment. I was only at the hospital for a short while, but I didn't like being moved around so often. I'm now eating and feel much better and stronger. My mother stayed strong throughout the whole process and she had a very good support network. I hope to start afresh one day and forget about it all, so I help my mother around the home, watch movies and take it easy.”
- **“I am on the road to recovery.** I attend groups, meetings, events, everything possible to get better. I have a family who I need to get better for. A situation at work pushed me mentally, I left my home one night to commit suicide, but something made me think of my children and I phoned 111 and asked for help. They advised to go to A&E. When I went they were fantastic. A mental health nurse was on shift. This was the start of my recovery the big part is admitting that I had a problem. I take medication now which is helping. Being mentally ill is not wrong – more awareness of mental health please and support for families dealing with a mental illness. People need to know that if they are feeling suicidal there is help out there.”
- **“I still have a job but I suffer from anxiety and stress because of financial difficulties.** I moved over from Nigeria and my marriage fell apart. I stopped seeing my children, as the mother would not allow this. I feel a bit better now, as my job still calls me for work. I feel like I have let my family down sometimes. It causes me to be very worried and I don't want to have a heart attack.”
- **“I am much calmer, but still hearing the voices.** I never told my GP until it got really bad. I started to feel enclosed, isolated and that people were staring at me.

Finally, I had a panic attack. What helped was my GP and the hospital staff who put me on medication. I love when my family are around and I have just started going out. I want to drive my car, but I'm not allowed due to the medication. I'm sorry I never got to see my son graduate from university the other day and my other younger son needs my support. I need to get stronger. I would love to get better, go back to church and to normal life."

- **"I have Post Traumatic Stress Disorder**, but I'm not getting the anti-psychotic drugs I need. I am outraged; I'm one of many of hundreds and thousands in the land suffering. I would have had 6 months intensive treatment pre-2008 but I'm getting nothing now. A lot of the voluntary sector programmes have closed down too or have been reduced. I know I've got a lot to do but it's tough to do with no support."
- **"My schizophrenia was diagnosed when I was 19, thirty years ago.** When I was diagnosed I received wonderful support at the Maudsley. I get stressed sometimes, but I manage well. I get medication from my GP and my community psychiatric nurse helped a lot. The family and church also help a lot. The NHS has helped me considerably and I can't thank them enough. I don't have a nurse or consultant anymore. I'm glad as it means I'm well."
- **"I had a traumatic experience nine years ago.** I had an assault on me and suffered from Post Traumatic Stress Disorder and depression. My GP referred me to Cognitive Behaviour Therapy and counselling. I struggle a bit from saying no to people and trusting them. I feel at peace in myself now. What helps is going to the gym, taking a steam and sauna, swimming, visiting old friends, socialising, helping people in need and going to church. If someone was at the beginning of my experience, my advice would be to take time to heal and it is good to talk – don't hold it in."

**The Health and Wellbeing Board welcomes your views.
You can email us at PHAdmin@southwark.gov.uk**