

Southwark Carers' Needs

Southwark's Joint Strategic Needs Assessment

Knowledge & Intelligence Section

Southwark Public Health Division

January 2021

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GATEWAY INFORMATION

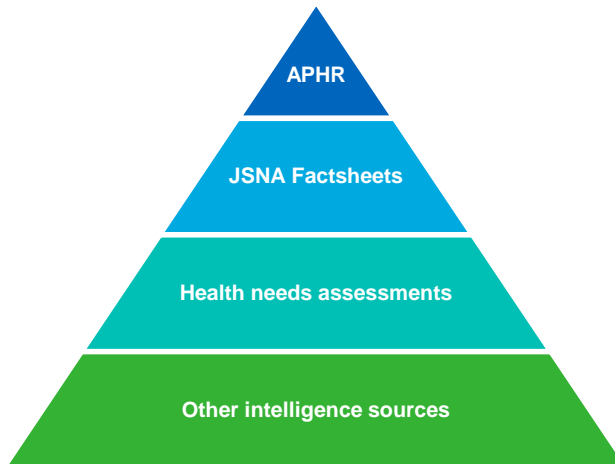
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Needs assessments form part of Southwark's Joint Strategic Needs Assessment process

BACKGROUND

The Joint Strategic Needs Assessment (JSNA) is the ongoing process through which we seek to identify the current and future health and wellbeing needs of our local population.

- The purpose of the JSNA is to inform and underpin the Joint Health and Wellbeing Strategy and other local plans that seek to improve the health and wellbeing of our residents.
- The JSNA is built from a range of resources that contribute to our understanding of need. In Southwark, we have structured these resources around four tiers:



Tier I: The Annual Public Health Report provides an overview of health and wellbeing in the borough.

Tier II: JSNA Factsheets provide a short overview of health issues in the borough.

Tier III: Health needs assessments provide an in-depth review of specific issues.

Tier IV: Other sources of intelligence include Local Health Profiles and National Outcome Frameworks.

- This document forms part of those resources.
- All our resources are available via: www.southwark.gov.uk/JSNA

This needs assessment aims to evaluate the unmet needs of Southwark's unpaid carers

AIMS & OBJECTIVES

This Southwark Carers' JSNA aims to identify the current and potential future health and social care needs of unpaid carers in Southwark, and to provide recommendations to policy makers in order to improve current pathways and provision and to address gaps in support.

Objectives of the Carers' JSNA are to:

- Identify the size and profile of the carer population in Southwark.
- Understand the diversity of different Southwark carer groups, and the specific (and varying) demands, burdens and risks experienced.
- Identify more vulnerable carer groups.
- Assess the health and social needs of carers in Southwark.
- Explore the views of local community groups and stakeholders regarding the needs of carers and current provision.
- Work with Adult Social Care colleagues to map out existing service provision and care pathways in the borough.
- Develop recommendations in partnership with Southwark Carers Board (or delegated Task & Finish Group) for improvements to pathways and provision.
- Raise awareness of the nature of caring, and what constitutes a carer.

The Carers' JSNA addresses the needs of unpaid child and adult carers living in Southwark or registered with a Southwark General Practitioner (GP).

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Southwark unpaid carers contribute £447m per year, but often at great personal cost, against increasing pressures

INTRODUCTION

Southwark has at least 25,700 unpaid carers,^{1,2} whose contribution is immense but often comes at a high personal cost. Pressures on carers are increasing due to demographic, legislative and public funding changes. Carers need support.

- 'Carer' is defined in this report as a child or adult providing unpaid care (extra definition restrictions are explained).
- Almost two in three UK adults (65%) will provide unpaid care at some stage (70% of women, 60% of men).³
- Carers make a huge contribution to Southwark health and wellbeing; in 2019, their work was valued at £447m per year.⁴ This care enables cared-for residents to remain well and more independent for longer, and reduces the need for social and health interventions. Without unpaid carers, social services and the NHS would collapse.⁵
- However, this often comes at a high personal cost: many carers are lonely, isolated, and struggling with their own health, work and finances. In a 2019 survey of UK carers,⁶ one-quarter reported having a disability, almost half had provided care for 10 or more years, and a similar proportion provided 90 hr of care or more each week.
- Pressures on carers are accelerating due to population ageing, increasing pension age, and shrinking health and social service budgets (despite evidence for strong return on investment⁷). Carers need support to enable them to continue their vital work.
- This Carers' JSNA aimed to establish Southwark carers' current needs and supports, and to recommend effective support developments for the future. Recommendations will help shape the Southwark Council Carers' Pathway and Wellbeing Hub development, and wider health and social care service delivery.

References

1. Census 2011. ONS, 2019.
2. Interim 2015-based Borough Preferred Option population projections. Greater London Authority, 2017.
3. Will I care?: The likelihood of being a carer in adult life. Carers UK, 2019.
4. Based on 2019 Southwark estimated carer numbers (see later slides) and 2015 UK-wide unpaid carer contribution (Facts About Carers, Carers UK, 2019).
5. Facts About Carers: Policy Briefing August 2019. Carers UK, 2019.
6. State of Caring: A snapshot of unpaid care in the UK. Carers UK, 2019.
7. First Contact: Identifying Needs and Assessment. Association of Directors of Adult Social Services, 2019. London Borough of Newham identified a £5.90 equivalent reduction in local authority cost for every £1 invested in carers.

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Since 2014, legislation has sought to align carers' rights with those of the person they care for

NATIONAL GOVERNMENT POLICY CONTEXT: CARE ACT 2014 INTENTIONS

“The Care Bill [Care Act 2014] in many respects marks a quiet revolution in our attitudes towards, and expectations of, carers. At last, carers will be given the same recognition, respect and parity of esteem with those they support. Historically, many carers have felt that their roles and their own wellbeing have been undervalued and under-supported. Now we have a once in a lifetime opportunity to be truly acknowledged and valued as expert partners in care.”

Dame Philippa Russell
Chair, Standing Commission on Carers



Care Act 2014

Reference

Factsheet 8: The Law for Carers. Guidance: Care Act Factsheets, Department of Health & Social Care, 2016.

The Care Act 2014 requires local authorities to identify and assess carers, and to provide advice and support

NATIONAL GOVERNMENT POLICY CONTEXT: CARE ACT 2014 OVERVIEW

The Care Act of 2014 created a legislative basis for statutory carer support, prompting national and local policy and service initiatives.

- Local authorities need to work with their communities and provide or arrange services that help to keep people well and independent. This should include identifying local support and existing resources, and helping people to access them.
- Local authorities need to provide comprehensive information and advice about care and support services in their local area.
- Local authorities must provide or arrange services that help prevent people developing needs for care and support, or delay people deteriorating such that they need ongoing care and support.
- Local authorities must consider identifying local carers who might have support needs that are not being met.
- Local authorities have a responsibility to assess carers' support needs, where those carers appears to have such needs. This assessment will consider the impact of caring on the carer.
- If the carer is eligible, they and the local authority will agree a support plan which sets out how the carer's needs will be met. It may be that the best way to meet a carer's needs is to provide care and support directly to the person they care for.
- If eligible, carers should receive a personal budget, which is a statement showing the cost of meeting their needs.



Care Act 2014

Reference

The Care Act 2014. The Stationery Office.

The Southwark local carers' strategy was informed by carers, and sets out a number of shared priorities

LOCAL GOVERNMENT POLICY CONTEXT: COUNCIL CARER PRIORITIES

The Southwark Council 2013 carers' strategy, 'Valuing Carers in Southwark', was developed with carer input and explained the Council's shared priorities:¹

- Identifying and reaching more carers, early in their caring role, and offering the right information and support in the right way.
- Supporting carers' physical and mental health and wellbeing.
- Helping carers to have fulfilled lives beyond their caring responsibilities.
- Making sure carers have choice and control over the services they use.
- Supporting young carers and protecting them from caring which harms their wellbeing and development.

This strategy was reviewed in August 2018 and July 2019:^{2,3}

- Progress was reported around carer identification, advice, health support, respite, emergency planning, young carers, and complementary council–NHS working.
- Recommendations covered: service development; emergency planning; young carers; and access to education, employment and leisure.



References

1. Valuing Carers in Southwark. Southwark Council, 2013.
2. Valuing Carers in Southwark: Progress on achievements against pledges. Southwark Council, 2018.
3. Briefing Note: Joint Southwark Carers Strategy. Southwark Council, 2019.

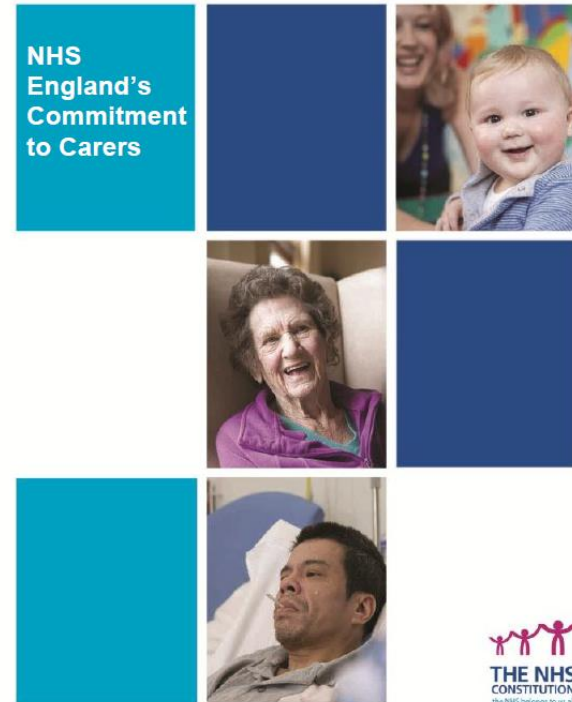
NHS England's commitment to carers is based around eight priority areas

NATIONAL NHS POLICY CONTEXT: 'COMMITMENT TO CARERS'

In 2014, NHS England published 'NHS England's Commitment to Carers', setting out the NHS national approach to carers.



- The Department of Health & Social Care's mandate to NHS England included ensuring that NHS England improves the involvement of carers, as well as patients, in care.
- Based on emerging themes, NHS England developed 37 commitments around the following eight priorities, which are within NHS England's gift to deliver and move forward:
 1. Raising the profile of carers
 2. Education, training and information
 3. Service development
 4. Person-centred, well coordinated care
 5. Carer identification and support in primary care
 6. Commissioning support
 7. Partnership links
 8. NHS England as an employer



Reference

NHS England's Commitment to Carers. NHS England, 2014.

Local hospital care providers are developing carer policies and frameworks to facilitate better support

LOCAL NHS POLICY CONTEXT: HOSPITAL CARER POLICIES

Southwark hospital care providers are developing their own carer support strategies.

- South London and Maudsley NHS Foundation Trust (SLaM) runs an annual Family and Carers Listening Event. They also have a Family and Carers' Strategy 2015–2019, a Families and Carers Handbook, and a Carers' Charter, which specifies that carers will:¹
 - Be recognised, respected and encouraged regarding their role and expertise.
 - Be involved in care planning and agreement of their cared-for person's care plan, where possible.
 - Get the information and advice they need to provide care, and be advised of their service entitlement.
 - Receive a 'Carers Engagement and Support Plan' which recognises and responds to their needs.
 - Get help and support when they need it.
 - Be involved in service planning, development and evaluation.
- Guy's and St Thomas' NHS Foundation Trust (GSTT) has a Carers' Policy and Carers' Passport to improve carer support. Policy commitments include:²
 - Acknowledging and valuing the vital role carers play in the health and wellbeing of the people they care for.
 - Recognising carers' valuable information on their cared-for person's condition, needs and wishes, and their possible wish to help with in-patient and post-discharge care.
 - All carers will be identified, involved, informed, respected, supported, and trained if appropriate, as partners in care.
 - All carers will be given information in an appropriate, accessible format, plus access to the Carers' Passport.
- King's College Hospital is also developing a carer strategy.³
- NHS carer engagement and support plans currently do not link with council social services carer support.

References

1. Patients and Carers: Carer Information. South London and Maudsley NHS Foundation Trust, 2019.
2. Trust Policy: Carers' Policy. Guy's and St Thomas' NHS Foundation Trust, 2015.
3. Board of Directors Agenda and Papers Oct 17 2019. King's College Hospital, 2019.

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UK-wide, carers' work is valued at £132bn a year, but they face mounting pressures and dwindling support

THE NATIONAL PICTURE

Recent UK-wide carer research reports mounting pressures on carers and services.

- Carer numbers, age and hours are rising.¹ Carers are more often female. BAME carers work longer and are supported less.¹
 - Most carers (58%) are women. Their paid work is more likely than men's to be impacted by their caring. Over 36,000 women work, care for 35+ hr a week and raise children. Female carers need support to stay in work and avoid poverty in old age.²⁻⁴
 - Nationwide, 65+ yr old carers' numbers increased 43% between 2011 and 2019.²
 - Young carer numbers have risen, especially in poorer families, as external support dwindles. Young carer identification has improved but specialist support funding has not kept pace. Their health and life chances are still at risk.⁵
- Carers save the nation a huge amount, but face substantial financial challenges themselves.
 - UK unpaid carers' support is valued at £132bn a year.²
 - Over one-third of carers (39%) have financial challenges. Of these, three-quarters (78%) regularly pay caring expenses themselves.²
 - One-fifth of carers (22%) live in poverty.¹ Over half of carers yet to retire (53%) are unable to save for their retirement.²
 - One in seven carers also work. Longer working ages mean more staff juggling work and caring. Employer support for carers varies (private sector support is less). Growing numbers are leaving: 600 UK carers a day leave work due to caring pressures.^{2,3}
- Carers often do not receive the support they need, with negative health effects.
 - Only one-quarter of carers (27%) received a carer's assessment or review last year.²
 - One in eight carers (12%) (or their cared-for person) get less support now than a year ago, due to funding cuts.² Over three-quarters of local authorities (78%) reduced their carers' respite spending level over the last year.⁶
 - Very few carers (8%) had sufficient breaks over the last five years: over half (54%) had none. One-third (33%) would use a break to attend their own medical appointments.⁶
 - Many support services have reached crisis point due to local and national funding reductions.²
 - Four-fifths of carers can't get the exercise they want and are lonely or isolated.² Over half (61%) report worse health due to caring.
 - Over one-third (37%) of carers' cared-for people underwent emergency hospital admission last year; half these admissions were preventable with more care or support, carers felt.²

References

1. Facts About Carers: Policy Briefing August 2019. Carers UK, 2019. BAME = Black, Asian and minority ethnic.
2. State of Caring: A Snapshot of Unpaid Care in the UK. Carers UK, 2019.
3. Juggling Work and Unpaid Care: A Growing Issue. Carers UK, 2019.
4. Breaking Point: The Social Care Burden on Women. Age UK, 2019.
5. Still Hidden, Still Ignored: Who Carers for Young Carers? Barnado's, 2017.
6. Carers at Breaking Point: Making the Case for Carers' Breaks in England. Carers UK, 2019.

Nationally, most council-supported carers are middle-aged or older, female, isolated, stressed and doing long hours

THE NATIONAL PICTURE

The 2018/19 Survey of Adult Carers in England reported on adult carers in contact with council services, regarding their demographics, employment, caring burden, and health and support experience.

- This survey reported on English adult carers of adults, who received council carer assessment or support in the past year.
 - These carers are likely to experience a heavier caring burden, as a group, than carers reported in the Family Resources Survey (see next slide).
 - Sampling (including randomisation) and reporting were performed by the council, and excluded those who were in dispute with the council or who preferred not to be surveyed.
 - Results were weighted to be representative of the whole eligible population of carers in England.
- Most carers were aged 45–84 yr (80%): 55–64 yr olds made up the biggest group (24%). Older carers tended to care for older people.
- Over two-thirds of carers (68%) were women.
- Most carers (65%) had been caring for over five years; almost one-quarter (24%) had been caring for 20 yr or more.
- More than three-quarters (76%) spent more than 20 hr per week, over half (54%) spent 50+ hr per week, and over one-third (39%) spent 100+ hr per week.
- Almost one-quarter (24%) of carers were employed (10% full-time). Almost half (47%) had caring-related financial difficulties.
- Carers' cared-for person had: a physical disability (51%), long-standing illness (40%), dementia (35%), problems connected to ageing (33%), sight or hearing loss (29%), a mental health problem (22%), learning disability (LD) or difficulty (21%), terminal illness (6%), and/or alcohol or drug dependency (2%).
- Well over half of all carers (61%) said caring caused them stress, two-thirds (66%) reported disturbed sleep, almost one-half reported depression (45%) or anxiety (43%), around one-third reported physical strain (35%) or needing GP care (29%), and over one-fifth said caring triggered onset of a health condition (24%) or worsened an existing health condition (21%).
- Two-thirds did not receive enough social contact (69%) or support and encouragement as carers (66%); over three-quarters (78%) did not have enough control over their daily life; and half (50%) didn't look after themselves adequately.
- Almost one-sixth (14%) of carers were dissatisfied with the social services they and their cared-for person had received in the last year.

Reference

Personal Social Services Survey of Adult Carers in England 2018-19. NHS Digital, 2019.

Slide 15

UK-wide, carers are most likely to be middle-aged or older, female, and supporting an older parent or spouse

THE NATIONAL PICTURE

The 2017/18 Family Resources Survey reflected all UK carers' experience regarding their demographics, employment, caring burden and cared-for person.

- This survey reported on a random sample of occupants of UK households, including carers.
 - These carers included those in contact with council support services and those not.
 - Therefore, these carers were likely to experience a lighter caring burden, as a group, than those reported in the Personal Social Services Survey of Adult Carers (see previous slide).
- The proportion of unpaid (all-ages) carers in the population fell between 2012/13 and 2017/18; the respective drop was: 10% to 8% for females; 7% to 6% for males; and 9% to 7% for all carers.
- Most caring was done by people aged 45 to 84 yr; 55–64 yr olds made up the largest group (15% of same-age population). However, 3% of all children and young people (24 yr or younger) were carers.
- One-third of adult carers (32%) gave 5–19 hr per week, one-fifth (21%) gave 0–4 hr, and one-sixth (16%) gave 50+ hr.
 - The prevalence of carers working 50+ hr was less than reported in the Personal Social Services Survey; a heavier caring burden among respondents to the latter survey is likely to play a part in this difference.
- Adult carers were less likely to be in employment (51% of carers) and in full-time employment (32%), and more likely to work part-time (18%), compared with all adults (61%, 47% and 14%, respectively). However, wages or salaries were by far the commonest main household income source for most adult carers (48%). One-third of adult carers (34%) took home less than £200 per week (net). Male carers earned more than female carers.
 - The prevalence of carers in employment (and full-time employment) was higher than that reported in the Personal Social Services Survey; a heavier caring burden among respondents to the latter survey is likely to play a part in this difference.
- More carers supported someone outside (56%) versus inside (47%) their home. The cared-for person was most likely to be a parent (39%), followed by spouse/spouse-equivalent (20%), child (15%), other relative (10%) or non-relative (8%). Eight per cent of carers cared for more than one person.
- Cared-for people were most likely to be aged 75+ yr (46% of all cared-for people) (for 85+ yr, 33%; for 75–84 yr, 13%). Of people receiving care at least once a week, almost two-thirds (62%) received care either continuously (41%) or several times a day (21%). Household wages or salaries were by far the commonest main income source for cared-for people (61%).

Reference

Family Resources Survey, 2017/18: Care. Department for Work & Pensions, 2019.

Current Southwark carer estimates range from 25,700 to 48,100, rising at least 14% over the next 10 years

THE PICTURE IN SOUTHWARK: RESIDENT CARER NUMBERS

The estimated number of people currently providing unpaid care varies substantially, from 25,700 to 48,100, and is expected to increase by at least 14% over 10 years. Southwark has a lower proportion of carers than its closest statistical neighbours, London and England.

- In 2011, the proportion of Southwark residents identifying as a carer (7.2%) was slightly lower than in 2001 (7.6%), and less than the average for its closest statistical neighbours¹ (7.4%), London (8.4%) and England (10.2%).²
- Estimates of current and future numbers of Southwark carers vary substantially depending on prevalence source:²⁻⁵

Source	Unpaid carer definition	UK carer %	Southwark carer numbers			Southwark carer % increase 2020–30
			2020	2025	2030	
Census 2011 ²	All ages. Looking after, helping or supporting family, friends, neighbours or others.	12%	25,700	28,100	30,000	17%
Understanding Society survey 2018 ⁴	Adults only. Looking after or giving special help to someone you live with who is sick, disabled or elderly, or providing a regular service or help to any sick, disabled or elderly person not living with you.	15%	42,400	46,000	48,400	14%
Carers UK survey 2019 ⁵	Adults only. More comprehensive definition, including unrecognised activities such as emotional support or arranging care.	17%	48,100	52,100	54,900	14%

References

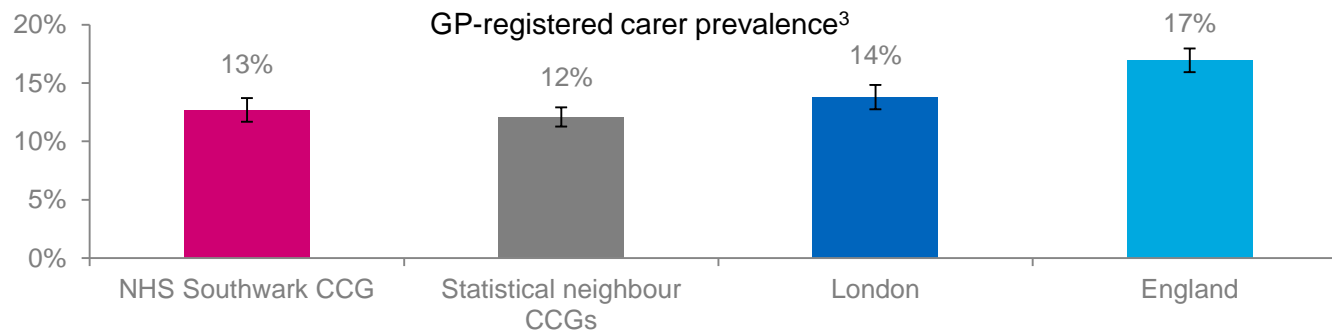
1. Closest statistical neighbours = average result for Lambeth, Tower Hamlets, Hackney and Lewisham.
2. Census 2011. ONS, 2019. Carer numbers based on age-group-specific Southwark (not UK) carer rates.
3. All carer number estimates calculated using the Interim 2015-based Borough Preferred Option population projections, GLA, 2017.
4. Understanding Society 2018. Institute for Social and Economic Research. Carer numbers based on UK adult (16+ yr) carer rates.
5. Juggling Work and Unpaid Care: A Growing Issue. Carers UK, 2019. Carer numbers based on UK adult (16+ yr) carer rates.

Approximately 35,400 adult Southwark GP patients are carers

THE PICTURE IN SOUTHWARK: GP-REGISTERED CARER NUMBERS

Approximately 35,400 adult Southwark GP patients are carers.

- In July 2019, 13% of adult Southwark GP patients answering the GP Patient Survey reported they were unpaid carers. Levels were lower than in England, and similar to London and the average for the four closest statistical neighbour Clinical Commissioning Groups (CCGs).^{1,2}



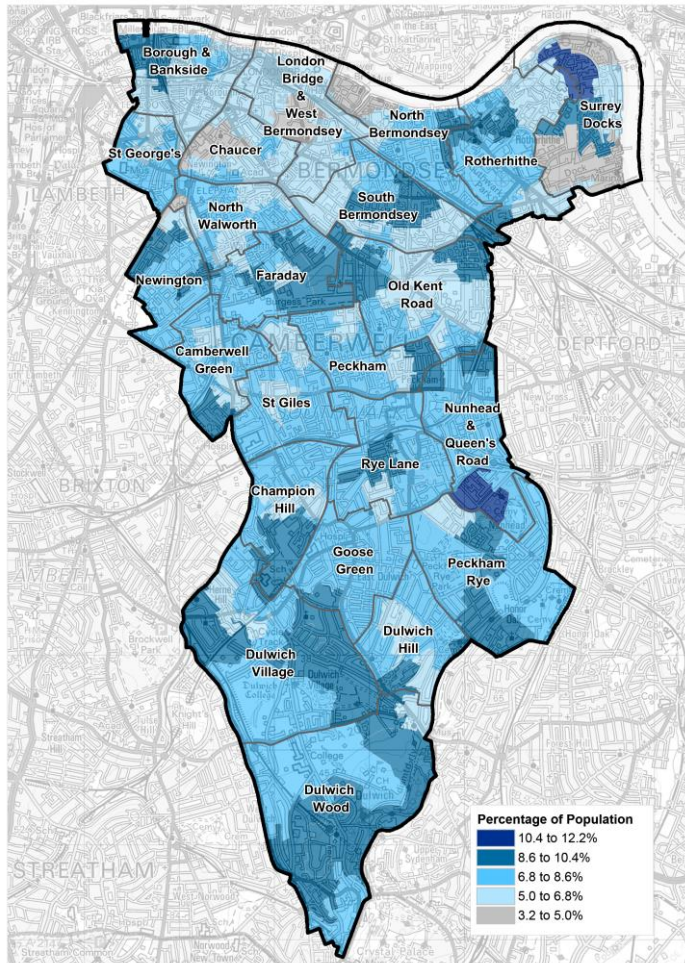
- These results suggest that about 35,400 current Southwark GPs patients are unpaid carers (but statistical probability indicates that numbers could be as low as 32,700 or as high as 38,300).
- Note that numbers of Southwark GP-registered carers would be expected to differ from numbers of Southwark resident carers. This is because GP patients can travel across borough boundaries to attend their preferred GP, and as a group are older than the general population.

References

1. GP Patient Survey July 2019. NHS England. There were about 4100 Southwark respondents to the carer survey question. 'Caring' = Looking after or giving help or support to family members, friends, neighbours or others because of either long-term physical or mental ill health/disability, or problems related to old age (not counting anything done as part of paid employment).
2. In 2019, Southwark's closest statistical neighbour CCGs were Lambeth, City & Hackney, Lewisham and Haringey. (Public Health Outcomes Framework. Public Health England, 2019.)
3. Here and elsewhere, non-overlapping whiskers indicate a 95% probability of a real difference between groups. Confidence intervals prepared using: Analytical tools for public health: Common public health statistics and their confidence intervals. Public Health England, 2018.

In 2011, Southwark had localised pockets of higher carer levels, spread throughout the borough

THE PICTURE IN SOUTHWARK: RESIDENT CARER LOCATION



Results from the 2011 Census showed that the proportion of Southwark residents who reported they were carers varied substantially across the borough.¹

- Carer levels in each neighbourhood area² varied substantially, from one-eighth (12%) to under 1/30th (3%) of residents.
- Localised pockets of higher carer prevalence (i.e. 9% of residents or more) were spread throughout the borough.

References

1. Map contains National Statistics and OS data © Crown copyright and database right 2019.
2. 'Local Super Output Areas' containing between 1,000 and 3,000 people.

Carers are more likely to be female, and 78% are of working age. Future numbers will rise, especially for older carers.

THE PICTURE IN SOUTHWARK: CARER GENDER & AGE

There are more female than male Southwark carers (39% more at working age).¹ At least 2,600 carers are aged 0–24 yr. Most carers (78%) are working age. In 10 years, there will be an estimated 9% more 16–24 yr, 20% more 35–49 yr and 45% more 65+ yr carers.

- In 2019, more Southwark females than males are estimated to be unpaid carers – 40% more at working age:^{1–3}

Age	Female carers	% of all females	Male carers	% of all males
0–24 yr	1,400	3%	1,300	2%
25–49 yr	7,100	9%	5,200	6%
50–64 yr	4,700	18%	3,300	13%
65+ yr	1,600	11%	1,500	12%
All ages	14,800	9%	11,200	6%

- Future age-based carer number estimates (based on population change alone) are:^{1,2}

Age	2011 carer %	2020 carers	2025 carers	2030 carers	% increase 2020 to 2030
0–15 yr	1%	600	700	700	8%
16–24 yr	5%	1,900	2,000	2,100	9%
25–34 yr	5%	4,100	4,200	4,100	1%
35–49 yr	10%	8,100	9,200	9,700	20%
50–64 yr	16%	7,900	8,500	9,000	14%
65+ yr	11%	3,000	3,600	4,300	45%
All ages	7%	25,700	28,100	30,000	17%

References

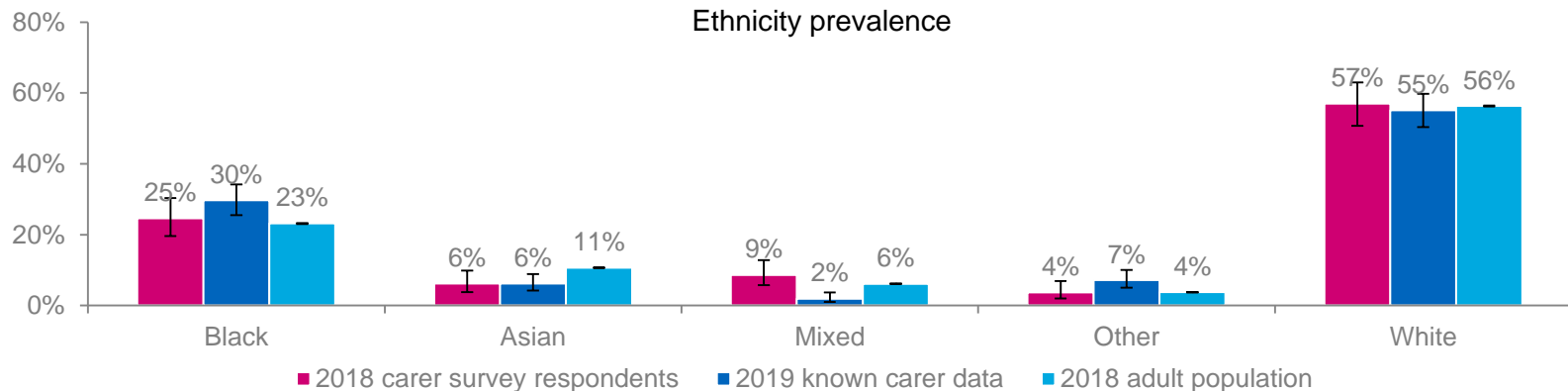
1. Census 2011. ONS, 2019. 'Working age' = 25–64 yr.
2. Interim 2015-based Borough Preferred Option population projections. Greater London Authority, 2017.
3. Number summations and percentage calculations may be affected by rounding error.

Asian ethnicity prevalence seems lower than expected among known Southwark adult carers

THE PICTURE IN SOUTHWARK: CARER ETHNICITY

Southwark seems to have lower than expected levels of self-identified Asian adult carers known to services, compared with overall adult population estimates.

- The Survey of Adult Carers in England collects information from carers in all relevant English local authorities.¹ The 2018 survey included 263 responses from Southwark. Information is also collected by Adult Services for carers receiving support from the Council.²
- Both data sources seemed to indicate a statistically significantly lower prevalence of Asian ethnicity among known Southwark adult carers, compared with overall Southwark adult population ethnicity estimates.³ Other ethnicity comparisons had mixed results.



References

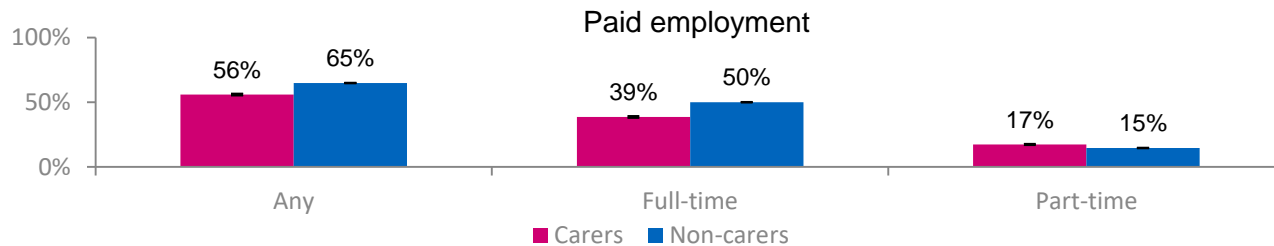
1. Personal Social Services Survey of Adult Carers in England: Data return for the 2018-19 survey year. NHS Digital (Health and Social Care Information Centre), 2019.
2. Mosaic Adult Social Services database. Southwark Council, 2019 (private communication).
3. 2016-based round of demographic projections: Local authority population projections – Trend-based ethnic group projections, central migration scenario, November 2017. Greater London Authority.

Southwark carers are less likely to work full-time or at all, compared with non-carers

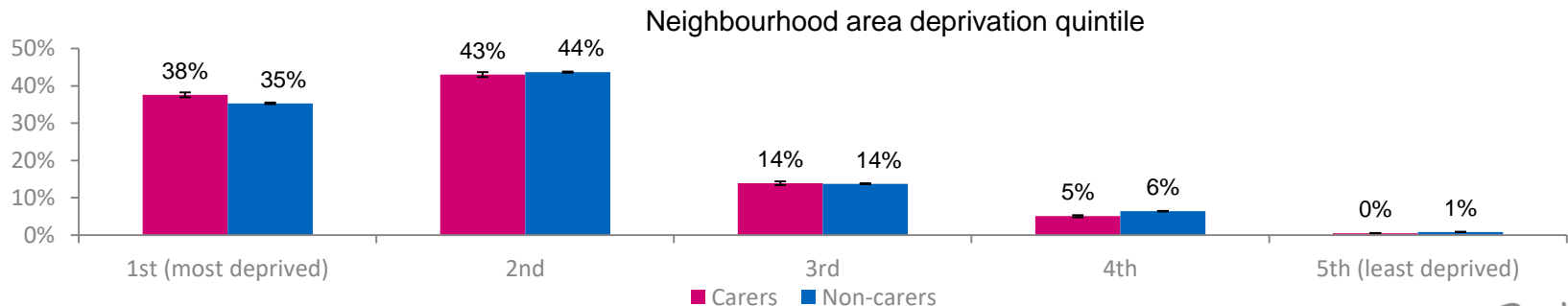
THE PICTURE IN SOUTHWARK: CARER INCOME & DEPRIVATION

In 2011, Southwark adult carers were less likely to work full-time or at all, more likely to work part-time, and more likely to live in the most deprived neighbourhoods, compared with non-carers.

- In 2011, adult carers were statistically significantly less likely to have full-time, or any, paid employment, and more likely to work part-time, compared with adult non-carers:¹



- Adult carers in 2011 were statistically significantly more likely to live in the most deprived Southwark neighbourhood areas ('first quintile'), and less likely to live in less deprived areas, compared with adult non-carers:^{1,2}



References

- Census 2011. ONS, 2019.
- English Indices of Deprivation, 2010. Department of Communities and Local Government, 2010.

Almost 6,000 people report giving more than 50 hrs of care a week, with older carers providing care for longer

THE PICTURE IN SOUTHWARK: CARER HOURS

Most carers report giving less than 20 hours' care per week, but the likelihood of giving more rises with age. In 2020, an estimated 5,900 people in the borough reported providing 50+ hours of unpaid care every week (i.e. many more hours than a full-time job).

- Weekly care hour loads for different carer age groups (showing 2011 carer proportions and estimated 2020 carer numbers) are at least:²⁻⁴

Carer age	2011 % of same-age carer population			2020 estimated carer numbers		
	1-19 hr	20-49 hr	50+ hr	1-19 hr	20-49 hr	50+ hr
0-15 yr	77%	11%	13%	500	100	100
16-24 yr	72%	15%	13%	1,400	300	300
25-34 yr	65%	17%	17%	2,700	700	700
35-49 yr	60%	18%	22%	4,800	1,500	1,800
50-64 yr	61%	16%	23%	4,800	1,300	1,800
65+ yr	44%	15%	42%	1,300	400	1,200
All ages	60%	17%	23%	15,500	4,300	5,900

References

- 'Working age' = 25 to 64 yr.
- Census 2011. ONS, 2019.
- Interim 2015-based Borough Preferred Option population projections. Greater London Authority, 2017.
- Number summation may be affected by rounding error.

7,200 Southwark carers (27%) are not in good health, almost double non-carer levels (14%), and worse than London levels

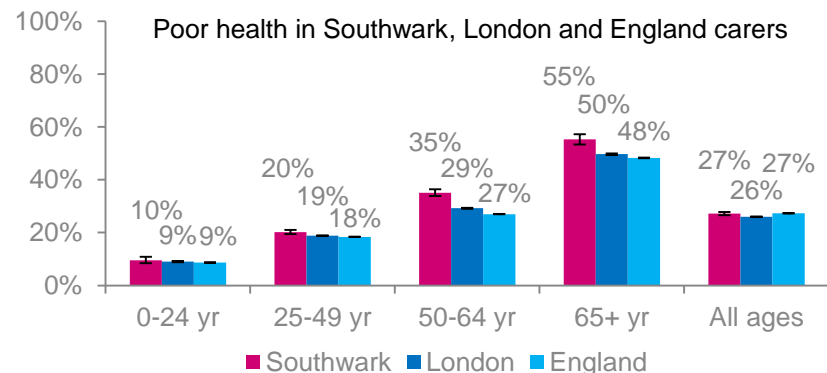
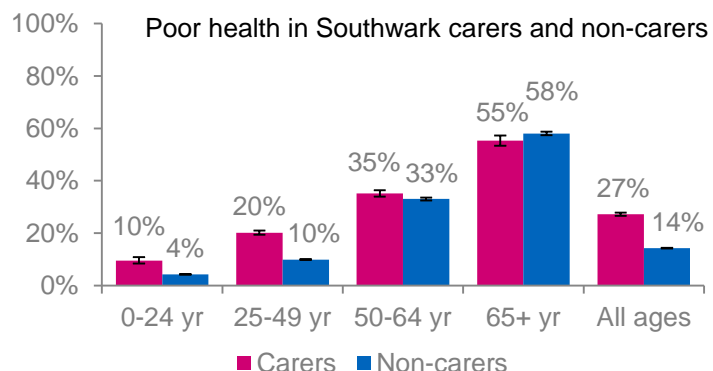
THE PICTURE IN SOUTHWARK: CARER HEALTH

Over one-quarter (27%) of Southwark carers are not in good health, almost double the level in non-carers (14%); this carer–non-carer gap is narrower in London and England.

- In 2020, at least 7,200 Southwark carers are not in good health, including about 300 young carers (based on 2011 rates).^{1,2}

Age	2011 % of same-age carer population			2020 estimated carer numbers		
	Good health	Fair health	Bad/very bad health	Good health	Fair health	Bad/very bad health
0–24 yr	90%	8%	2%	2,400	200	<50
25–49 yr	80%	15%	5%	9,800	1,800	600
50–64 yr	65%	26%	10%	5,200	2,000	800
65+ yr	45%	39%	16%	1,400	1,200	500
All ages	73%	20%	7%	18,800	5,300	1,900

- In 2011, levels of poor health (i.e. fair, bad or very bad) in all-age Southwark carers (27%) were almost double levels in non-carers (14%) (over double, for carers under 50 yr); the carer–non-carer health gap was narrower in London and England. Southwark had statistically significantly worse poor carer health levels in: (i) adults, versus London and England; and (ii) all ages, versus London.¹



References

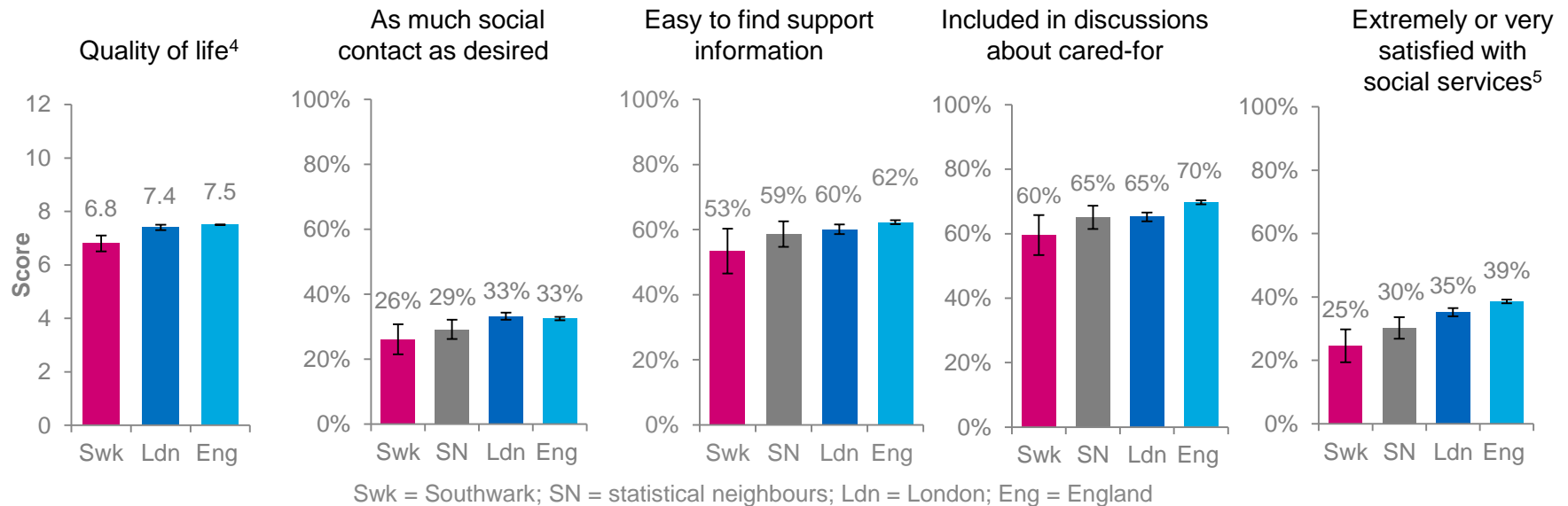
- Census 2011. ONS, 2019. 2020 estimations based on Census 2011 rates and 2015-based population projections.
- Interim 2015-based Borough Preferred Option population projections. Greater London Authority, 2017.

Carer quality of life, social contact and services satisfaction are low, and below London and England levels

THE PICTURE IN SOUTHWARK: CARERS' LIVES & SATISFACTION (1)

In 2018/19, Southwark carers' quality of life and satisfaction with social services were low, and well below London and England levels.

- In 2018/19, over half (60%) of Southwark carer survey respondents were satisfied with social services.¹ However, about three-quarters (74%) wanted more social contact. Carer quality of life was low. Almost half said they couldn't easily find support information and weren't included in discussions about their cared-for person.² London and England results were statistically significantly better for the five outcomes shown below; average statistical neighbour results were statistically similar.³



References

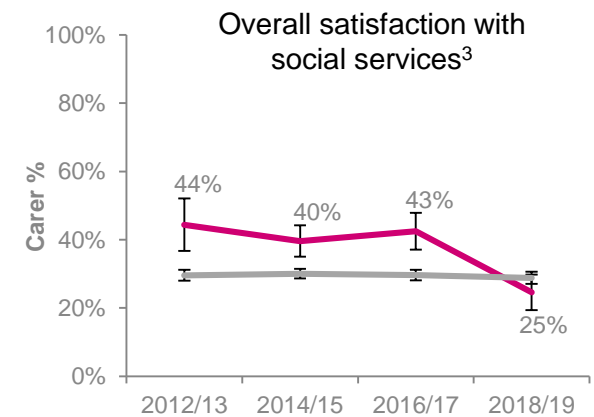
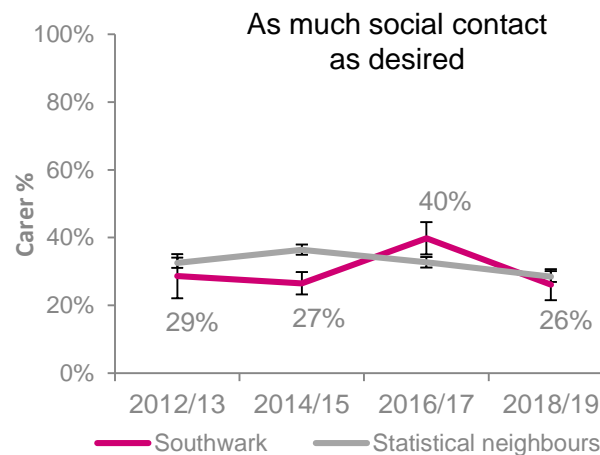
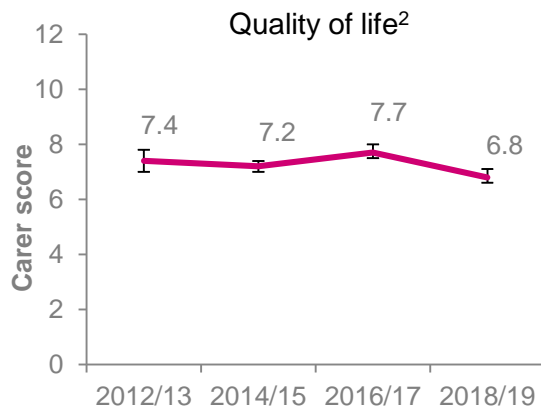
- Private communication, Southwark Council ASC staff, 2019. ('Satisfied' = extremely, very or quite satisfied.)
- Adult Social Care Outcome Framework 2018/19. NHS Digital, 2019.
- SN = average result for four closest statistical neighbours = Lambeth, Tower Hamlets, Hackney and Lewisham.
- Maximum score = 12. This is a composite measure reflecting level of need around: control, personal care, nutrition, accommodation, safety, social participation, occupation and dignity. Full statistical neighbour average results were not calculable.
- Extremely or very satisfied with social services support for carer and cared-for person = 'overall satisfaction with social services'.

Recently, Southwark carers' quality of life, social contact and social services satisfaction have declined

THE PICTURE IN SOUTHWARK: CARERS' LIVES & SATISFACTION (2)

Since 2016/17, Southwark carers' self-reported quality of life, social contact and overall social services satisfaction have seen a statistically significant decline (by one-eighth, one-third and two-fifths, respectively). In 2018/19, Southwark was no longer statistically significantly better than its statistical neighbour average for social contact and social services satisfaction.¹

- Southwark and average statistical neighbour trends for these survey questions, from the last four Surveys of Carers in England, are:¹



References

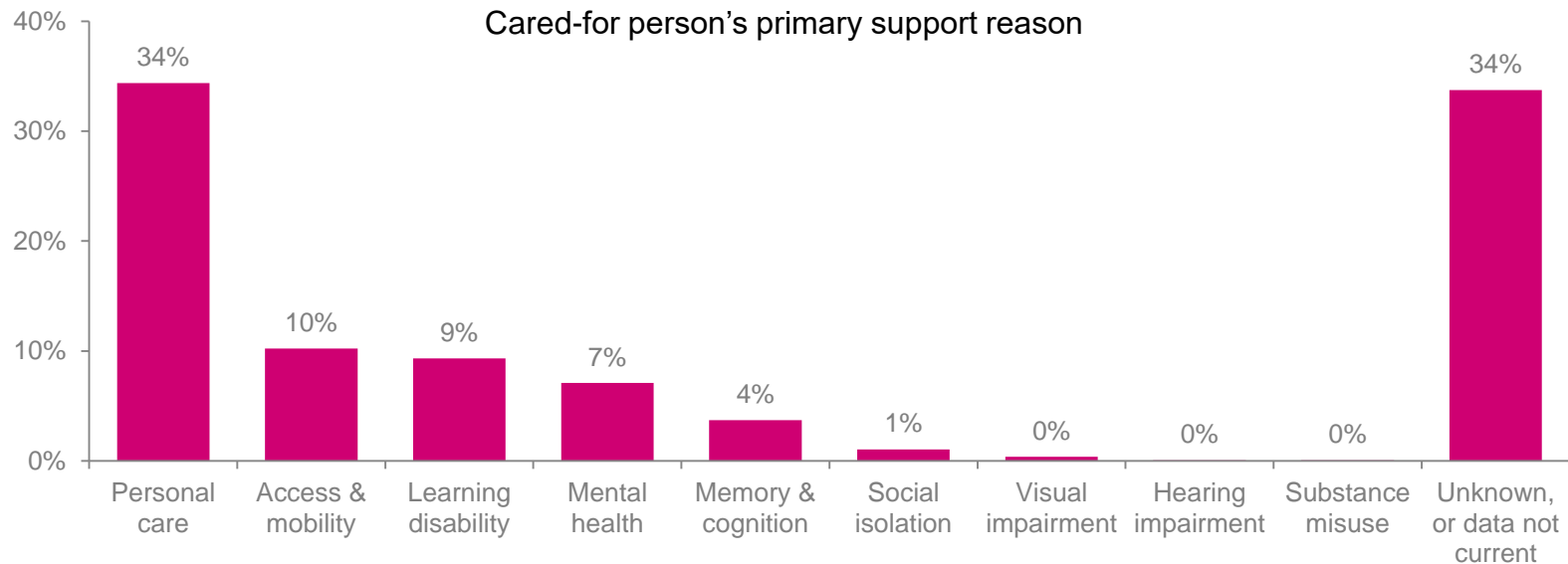
- Measures from the Adult Social Care Outcomes Framework (ASCOF), England, Time series of aggregated measures, 2010-11 to 2018-19. NHS Digital, 2019.
- Maximum score = 12. This is a composite measure reflecting level of need around: control, personal care, nutrition, accommodation, safety, social participation, occupation and dignity. Full statistical neighbour average results were not calculable.
- 'Overall satisfaction with services' = extremely or very satisfied with social services support for carer and cared-for person.

Carers known to Southwark Council are most commonly providing support around personal care

THE PICTURE IN SOUTHWARK: CARED-FORS' PRIMARY SUPPORT REASON

In 2018/19, the most common primary support reasons for Southwark Council's known carers' cared-for people appear to be personal care (34%), access and mobility (10%), LD (9%) and mental health (7%). One-third of known carers' cared-for people had no current data on support needs.^{1,2}

- Note that this survey data does not clarify: (i) the many different types of support covered by 'personal care', (ii) the carer's main reason for giving care, nor (iii) the type of support they actually provide. Data is incomplete so should be interpreted with caution.



References

1. Long-term support (LTS003). Southwark Council, 2019 (unpublished data).
2. Low levels of data coverage are probably affected by incomplete recording of carer and cared-for data during cared-for, carer and joint assessments, and incomplete linkage of carers' and cared-fors' data records.

The most common clinical support reasons of those requiring care are physical disability, long-standing illness and dementia

THE PICTURE IN SOUTHWARK: MAIN SUPPORT REASONS

In 2018/19, English carers' cared-for people's most frequent clinical reasons for needing support were physical disability, long-term conditions and dementia.¹ Local need will grow in the future.

Clinical support reason	English carers affected, 2018/19 (%) ¹	Estimated Southwark adults with clinical support reason ²			
		2020	2025	2030	% increase 2020–30
Physical disability	51%	16,000	18,100	19,900	28%
Long-standing illness	40%	103,000	113,200	121,500	21%
Dementia	35%	1,900	2,300	2,800	44%
Ageing problems	33%	5,300	6,200	7,300	43%
Sight/hearing loss	29%	Sight loss: 2,500 Hearing loss: 34,300	2,900 38,900	3,500 44,000	43% 32%
Mental illness	22%	53,100	57,500	60,500	17%
LD/difficulty	21%	6,900	7,400	7,800	16%

People with multiple long-term conditions have more complex support needs and are intensive users of health and social care services,³ including unpaid care.

- At least 16,000 Southwark GP registered patients have diagnosed multiple long-term conditions, dementia or ageing problems.⁴
- This group will grow in future, as people live longer but not necessarily healthier lives,³ increasing the demand for care.

References

- Personal Social Services Survey of Adult Carers in England: Reference tables for charts included in the SACE 2018-19 Report. NHS Digital, 2019.
- Future trend data sources: Projecting Adult Needs and Service Information, Projecting Older People Population Information, Institute of Public Care, 2019; Health Survey for England 2017 & 2018, NHS Digital, 2019; Projections of Older People with Dementia and Costs of Dementia Care in the United Kingdom 2019-40, London School of Economics and Political Science, Care Policy and Evaluation Centre, 2019; Prevalence of frailty and disability: findings from the English Longitudinal Study of Ageing, Gale *et al.* 2015; Adult Psychiatric Morbidity Survey 2014, NHS Digital, 2016; Interim 2015-based Borough-Preferred Option population projection, Greater London Authority, 2017.
- Long Term Conditions Compendium of Information. Department of Health, 2012.
- Unpublished data (Care Coordination Dataset). Guy's and St Thomas' Foundation Trust, 2019.

The most common support type provided to carers is information and advice

THE PICTURE IN SOUTHWARK: CARER SUPPORT DELIVERY

In 2018/19, the most common form of direct support provided to carers was information and advice; a few received residential respite.

- 2018/19 Southwark Council carer assessments (for carers of adults) were mostly joint assessments. Data is incomplete so should be interpreted with caution:
 - 51% of all known carers of adults (715 carers) appear to have received no assessment or review.¹
 - Of those who did, 72% (532 carers) appear to have received a joint assessment with their cared-for person, while 28% (204 carers) appear to have received a separate assessment.¹
 - 95% of carer assessments were begun within 2 months of the proposed start date, although 5% (25) were delayed longer (by up to 16 months).²
 - 89% of carer assessments were completed within 2 months, although 11% (52) were delayed longer (10% by up to 12 months, and 1% by up to 34 months).²
- In 2018/19, a small proportion of carers are believed to have received residential respite support (provided to the cared-for person). (Note that carers can receive a break from caring through other (non-residential) support provided to the cared-for person, but the relevant statistics are currently not recorded.)
- Actual council-funded respite levels were probably higher. Data for 2018/19 showed 74 service users receiving respite, all probably to benefit a carer, but accurate linkage of this data to carer records was not possible at the time of writing.³
- Some Southwark unpaid carers of children received 'Short Break' respite in 2018/19; uptake data was not available.³

References

1. Long-term support (LTS003). Southwark Council, 2019 (unpublished data).
2. Adult Social Services Mosaic dataset. Southwark Council, 2019 (unpublished data). Carer assessments completed between September 2018 and August 2019. No data available for other boroughs.
3. Private communications. Southwark Council ASC and Children & Adults Services staff, 2019.

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In 2018, an estimated 21,900 Southwark carers were unknown to services

THE SOUTHWARK RESPONSE: KNOWN VERSUS EXPECTED CARERS

In 2018, the great majority of Southwark carers (94%) were not known to Southwark Council services, especially young and working-age carers.

- Comparison of 2018 data on known Southwark carers¹ (this data is known to be incomplete) versus minimum expected total carers,^{2,3} by age group, shows:⁴

Age	2018/19 carers known to Southwark Council	2018 expected total Southwark carers	Difference	% of expected total carers known to Southwark Council
0–17 yr	20	1,000	980	2%
18–25 yr	50	1,660	1,600	3%
26–64 yr	1,030	17,870	16,830	6%
65–84 yr	290	2,500	2,210	12%
85+ yr	90	370	280	25%
Total	1,490	23,390	21,900	6%

Numbers are rounded to the nearest 10.

- Southwark Council staff are not expected to know every local carer.⁵

References

- Long-term support (LTS003). Southwark Council, 2019 (unpublished data).
- Census 2011. ONS, 2019.
- Population Estimates for UK, England and Wales, Scotland and Northern Ireland: Mid-2018. ONS, 2019.
- Some calculations are affected by rounding error.
- Private communication, Southwark Council ASC staff, 2020.

Southwark Council currently delivers carer support services both directly and via commissioned providers

THE SOUTHWARK RESPONSE: CURRENT CARER SERVICES

Southwark Council currently delivers carer support services both directly and via commissioned local provider organisations.

- Southwark Council carer support comprises: carer assessments, direct and part-direct payments, personal budget management, respite (for the cared-for person), advice and sign-posting, support (both one-to-one and via peer groups), and activities. Council support is described in the 'Support for Carers in Southwark' online leaflet.¹
- Council-commissioned carer services are provided by:
 - Southwark Carers
 - Citizens' Advice Southwark
 - Alzheimer's Society (for dementia carers)
 - Together for Mental Wellbeing (at Southwark Wellbeing Hub)
 - Contact (formerly Contact-a-Family, for parents of children with special educational needs and disabilities (SEND))
 - Change Grow Live (CGL) (for addiction carers)
 - Imago (for young carers)
 - Coram Voice (for young carers)
- Southwark carers can also access support from other healthcare and voluntary sector organisations, independent of Southwark Council, for example: Southwark GP practices (for all carers); GSTT (LD carers); Headway (brain injury carers); Opening Doors London (LGBT+ carers²); SLaM (mental health carers); Southwark Dementia Action (dementia carers); and Southwark Independent Voice (parent carers; 115 carers listed).
- The following slides outline Southwark Council funded carer support services in terms of their client eligibility, core offer, location, access times and recent activity.

References

1. Support for Carers in Southwark. Southwark Council, 2019
2. LGBT+ = Lesbian, gay, bisexual, transgender, and other non-heterosexual and non-cis-gendered identities.

Statutory carer assessments are delivered by Southwark Council staff directly

THE SOUTHWARK RESPONSE: CARER ASSESSMENTS

Carer assessments are a statutory responsibility of the Council, and are performed by Southwark Council Adult Social Care (ASC) staff directly.

- Eligibility: Carers can be eligible for support in their own right. The threshold is based on the impact their caring role has on their wellbeing. When determining carer eligibility, local authorities must consider the following three conditions:
 - The carer's needs for support arise because they are providing necessary care to an adult.
 - As a result of their caring responsibilities, the carer's physical or mental health is either deteriorating or at risk of doing so, or the carer is unable to achieve any of the outcomes as specified in the Care Act 2014.
 - As a consequence of being unable to achieve these outcomes, there is, or there is likely to be, a significant impact on the carer's wellbeing.
- Core offer: Statutory assessment for carers; support plan for carers; personal budget or direct payment for carers; and referral to other, council-funded carer services.
- Location and access times: Carer assessments can be provided at the carer's home, at the service provider's or social care office, or at another, mutually agreed venue; 9–5 Mon to Fri.

In recent years, carer assessment levels have not changed significantly.

- Over the last two years, numbers of completed carer assessments (and percentage of total known carers) were 719 (45%) in 2017/18 and 736 (49%) in 2018/19.

Reference

Private communication, Southwark Council ASC staff, 2019.

Southwark Council can arrange personal budget payments and respite for eligible carers

THE SOUTHWARK RESPONSE: CARER PAYMENTS AND RESPITE

Personal budget payments can be provided by Southwark Council, via direct and part-direct routes.

- Eligibility: Personal budget payments are provided by Southwark Council if carers are found to be eligible for help following their carer assessment.
- Core offer: Personal budget payment giving the carer money to spend on services (based on how much it will cost to arrange the care and support they need, in their local area). The personal budget payment is provided via:
 - Direct payment: Cash is paid directly into the carer's bank account; the carer then pays for services they receive;
 - Council management: Southwark Council pays for services the carer receives;
 - Third-party management: A third party arranges payment for services the carer receives; or
 - A mixture of the above options.
- Location and access times: Information on personal budget payments is available from: Southwark Carers (Walworth Methodist Church, 54 Camberwell Rd, Walworth SE5 0EN; 9–5 Mon to Fri); the Southwark Carers website; and the Southwark Council website.

Respite can be provided by Southwark Council, for eligible carers.

- Eligibility: Respite care is provided by the council for people who are normally cared for in their own home by a family member or friend who is not paid for their caring tasks, if that carer is found to be eligible for help following their carer assessment, or following the assessment of the person they care for.
- Core offer: Short-term, temporary respite care which gives the carer a break from their caring responsibilities. This respite care aims to enable personalised, high quality, informal care arrangements to be sustained. (Some local and national carer organisations may be able to help carers identify additional, non-council-funded respite opportunities, provided funding is available).
- Location and access times: Information on respite care is available from: Southwark Carers (Walworth Methodist Church, 54 Camberwell Rd, Walworth SE5 0EN; 9–5 Mon to Fri); the Southwark Carers website; and the Southwark Council website.

Reference

Private communication, Southwark Council ASC staff, 2020.

Southwark Carers and Citizens Advice Southwark are commissioned to provide general support

THE SOUTHWARK RESPONSE: GENERAL CARER SERVICES

Southwark Carers is commissioned to provide a wide range of carer services:

- Eligibility: People who identify as carers within the Southwark area.
- Core offer: Information, advice, outreach and peer support.
- Location and access times: Walworth (Walworth Methodist Church, 54 Camberwell Rd, SE5 0EN); 9–5 Mon to Fri, plus some weekend activities; also some 'pop-up' sites.
- Activity: In 2018/19, 326 new carers were registered (259 women and 67 men), and there were 4186 carer contacts, either directly (via face-to-face or phone contact) or indirectly (via website hits, mail-outs, text-shots or email requests).

Citizens Advice Southwark is commissioned to supply carer information and advice:

- Eligibility: People living, working or studying in Southwark who care for an adult or child with a long-term illness or disability.
- Core offer: Information and advice (including welfare benefits, housing, access to community care assessments and income maximisation).
- Location and access times: Bermondsey (8 Market Plc, Southwark Park Rd, SE16 3UQ; 10–1 Tues & Thurs); Peckham (27 Peckham High St, SE15 5RS; 10–1 Mon, Wed & Fri); Walworth (6–8 Westmoreland Rd, SE17 2AY); Camberwell (Sunshine House, 27 Peckham Rd, SE5 8UH; alternate Thurs sessions for carers of disabled children).
- Activity: In 2018/19, 1865 clients were assisted, in 1584 appointments; 1159 new carers were identified and 140 referrals received. Advice given meant that client carers would be £1,161,000 better off in the coming year.

Alzheimer's Society, Together, Southwark Council and Contact supply dementia, mental health and SEND carer support

THE SOUTHWARK RESPONSE: SPECIALIST CARER SERVICES (1)

The Alzheimer's Society is commissioned to provide dementia carer support:^{1,2}

- Eligibility: Carers of people with a diagnosis of dementia.
- Core offer: Information, advice and ongoing support.
- Location and access times: Rotherhithe (Time & Talent Centre, St Marychurch St, SE16 4JE); Nunhead (Green Community Centre, 5 Nunhead Green, SE15 3QQ); Office hours.
- Activity: In 2018/19, 115 carers were supported.

Together for Mental Wellbeing ('Together') and Southwark Council supply mental health carer support (at the Southwark Wellbeing Hub):^{1,2}

- Eligibility: Carers appearing to need extra support, who live in Southwark or are registered with a Southwark GP, and anyone in Southwark concerned about their own or someone else's mental wellbeing.
- Core offer: Client consultation; advice and sign-posting; referrals to local services; follow-up; one-to-one professional support; one-to-one volunteer peer support; professionally facilitated group support (led by Southwark Council staff); volunteer-led groups for practical support; group wellbeing workshops; identification of hidden carers and referral to Southwark Council ASC.
- Location and access times: One-to-one support: Southwark community location of carer's choice (e.g. library or café, but not the person's home), including Southwark Wellbeing Hub (29 Peckham Rd, Camberwell, SE5 8UA; 9–5 Mon to Fri). Mental health carer support group: Southwark Wellbeing Hub, 29 Peckham Rd, Camberwell SE5 8UA; second Tues of each month for 2 hr. Group peer support: community location of group's choice (e.g. library or café). Group wellbeing workshops: various Southwark locations.
- Activity: From Jul 2018 to Jun 2019, 30 carer referrals were received, 18 carers were redirected to the Southwark ASC mental health carers team, and 12 carers were served in-house. (Other carers also used the service but were not recorded as carers.)

Contact supports Southwark parents of children with SEND:^{1,2}

- Eligibility: Southwark parents with children (0–25 yr) with SEND and an Education, Health & Care Plan, or who receive support from the Children With Disabilities and Complex Needs or ASC team.
- Core offer: Group peer support; development and education sessions; information, advice and sign-posting.
- Location and access times: Camberwell (Sunshine House, 27 Peckham Rd, SE5 8UH); 10.30–12.30 Mon (drop-in), 1–4 Wed.
- Activity: From Jul 2018 to Jun 2019, carer support contacts were delivered via: coffee mornings (241 contacts); summer holiday programme (369); workshops (110); new referrals (29); sign-posting (40); case work (112); phone or email (231); and promotional events (53).

References

1. Private communications. Southwark Council commissioned service providers, 2019.
2. Private communications. Southwark Council ASC staff, 2019.

CGL (with HYP), Imago and Coram Voice support addiction carers and young carers

THE SOUTHWARK RESPONSE: SPECIALIST CARER SERVICES (2)

CGL delivers support to addiction carers, directly and via subcontracting to HYP:^{1,2}

- Eligibility: For CGL: adult carers of adult addiction clients. For Healthy Young People (HYP): young addiction carers; adult carers, family or 'significant others' of young person accessing HYP services for addiction support, where young person consents to carer's access; and adult carers whose cared-for young person refuses to access addiction support services.
- Core offer: CGL: Advice and support via one-to-one or family group support sessions; referral to other support agencies or networks. HYP: Support for young addiction carers; support for carers of young people; sign-posting to adult services to access family support; advice to adult carers whose cared-for young person refuses to access addiction support services.
- Location and access times: CGL: Camberwell (146 Camberwell Rd, SE5 0EE), 9.30–7 Mon, 9.30–5.30 Tues Thurs Fri, 1–5.30 Wed. HYP: community venue agreed by carer and young person, or their home (subject to risk assessment), daytime Mon to Fri (some evening flexibility).

Imago provides support to young carers:^{1,2}

- Eligibility: Children and young people (8–25 yr) resident in Southwark, with caring responsibilities for a relative with a long-term illness, disability, mental health condition, or drug or alcohol issue.
- Core offer: Assessment; professional and peer support; advice; referral to other services; socialising with other young carers.
- Location and access times: Surrey Quays (Unit 4, Upper Deck, Surrey Quays Shopping Centre, Redriff Rd, SE16 7LL), 8.30–5 Mon to Fri; clubs 10–1 last Sat of month.
- Activity from Jan to Dec 2018: 522 children and young people supported (67% 6–15 yr, 15% 16–17 yr, 18% 18–26 yr; 56% female, 43% male, 1% unknown gender or preferred not to say; 79% BME (56% black, 14% mixed, 7% Asian and 1% 'other'); caring for mother (58%), sibling (33%), father (5%), grandparent (2%) or more than one family member (1%).

Coram Voice offers advocacy for eligible young carers:^{1,2}

- Eligibility: (1) Young carers with advocacy needs and (i) 'Child In Need' or SEND eligibility or status, or (ii) a disclosure or allegation of child abuse, to children's services or as part of a child protection investigation. (2) Professionals referring a young carer.
- Core offer: Discussion about the caller's concerns and desired action, then sign-posting and advocacy to facilitate action.
- Location and access times: Freephone helpline 9.30–6 Mon to Fri, 10–4 Sat; contact via email, text and online messaging.
- Activity: From Apr to Sep 2019, no known Southwark young carers accessed the service.

References

1. Private communications. Southwark Council ASC staff, 2019.
2. Private communications. Commissioned service providers, 2019.

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Local carers have reported a heavy care burden, with significant health, social and economic impacts

COMMUNITY & STAKEHOLDER VIEWS: PREVIOUS LOCAL CARER RESEARCH

Research on local carers was recently done by Southwark Healthwatch (Dec 2018 to Apr 2019), using a survey and focus groups. Several themes emerged:¹

- Most unpaid carers provide multiple types of support and prolonged hours of care. Many don't feel well supported.
- Carers reported frequent negative impacts of caring on their health (physical and mental), finances, paid employment, home management, rest and relationships (including social isolation).
- Communicating with professionals was often a negative experience; mistrust of staff was common.
- Some instances of abusive and threatening care staff were reported. Some carers were afraid to report problems for fear of negative consequences.
- Finding and arranging support (both for the cared-for and carer) was stressful. Coordination between services needs improvement.
- Most carers had not received a carers' assessment, some despite requesting one. Those who had generally reported a negative experience.
- Respite was hard to access. Few carers received carers' support allowance; some who did reported unpredictable changes.
- Carers valued informal support networks, voluntary sector support, professional counselling therapy, and individual committed health and care professionals.

Other Southwark Healthwatch research found discrimination against LGBT+ carers:²

- In the 2018/19 Southwark LGBTQ+ Community Consultation, respondents who were carers reported experiencing homophobic discrimination from support staff.
- Many feared that disclosure of their own or their loved one's LGBT+ identity (including inadvertently due to dementia) would result in poorer treatment from care staff. They reported lack of staff understanding of LGBT+ carers' and cared-for people's needs.

The 2019 SLaM Family and Carer Listening Event attracted 89 people (carers, patients and professionals) to workshops and discussions. Themes included:³

- Carers' interaction with their cared-for people's clinical issues around: (i) dual psychiatric diagnoses and (ii) medication.
- Understanding and challenging stigma.
- Family issues affecting carers and their cared-for people.
- Carer confidentiality and communication.

References

1. The Impact of Caring on Unpaid Carers. Healthwatch Southwark, 2019 (pre-publication draft cited with permission; respondent numbers were 55 for survey, 19 for focus groups).
2. Southwark LGBTQ+ Community Consultation 2018-19. Healthwatch Southwark, 2019.
3. Private communication (Evaluation of the Family and Carer Listening Event, 28 June 2019). Southwark CCG, 2019.

Further local qualitative engagement has identified similar themes to the Healthwatch research

COMMUNITY & STAKEHOLDER VIEWS: NEW RESEARCH

For this Needs Assessment, 13 new stakeholder interviews were conducted, using semi-structured questioning, to better understand the needs of local carers.

- Interviewees represented both the 'carers' voice' and service providers:
 - 'Carers' voice' organisations:**
Opening Doors London (LGBT+ carers), Southwark Dementia Action Alliance (dementia carers), Southwark Independent Voice (parent carers)
 - Service provider organisations:**
Alzheimer's Society (dementia carers), CGL (addiction carers), GSTT (LD carers), Imago (young carers), King's College Hospital NHS Foundation Trust (acute brain injury carers), SLaM (mental health carers), Southwark Carers, Southwark Council (mental health carers), Southwark CCG (clinical lead on carers' needs), Southwark Wellbeing Hub

- Interview themes addressed:
 1. Impact of reduced services
 2. Increased needs of cared-for
 3. Especially vulnerable carers
 4. Mental health support
 5. Information support
 6. Coordination and practical support
 7. Respite
 8. Service development
 9. Data collection and development
 10. Wider developments

Current service provision was not felt to adequately meet local needs, with negative impacts on health

STAKEHOLDER THEME 1: IMPACT OF REDUCED SERVICE PROVISION

There was widespread agreement among stakeholders that current carer support services are not adequately meeting carers' needs, and with potentially negative impacts on carers' health.

- Many stakeholders reported that carer distress and social isolation are escalating.
- Non-statutory services are unable to bridge the gap.
- There is no dedicated carer crisis support service.
- Several service providers stated that they need improved, sustainable funding to adequately meet carers' needs, and to upscale.
- Stakeholders also reported they believed there had been a reduction in carer services in the borough.

Carers are financially vulnerable; a growing number of carers are giving up work to ensure care continuity and quality, but with limited financial support.

- Many stakeholders reported that carers need greater financial support to cover basic care provision, self-care and travel expenses (particularly if the cared-for person is in residential placement outside Southwark).

Stakeholders identified that the way in which service reductions and changes are managed and implemented could be improved.

- A number of stakeholders felt sudden and unpredictable changes caused added distress to carers.

The number of people requiring care, and the complexity and duration of their needs, is increasing

STAKEHOLDER THEME 2: INCREASED NEEDS OF CARED-FOR POPULATION

Cared-for people are living longer due to improved healthcare, but in poorer health. Stakeholders advised that carers are carrying a heavier burden, for longer.

- Cared-for people are living much longer than in the past, but are more likely (as a group) to have multiple health problems caused by: worsening of their initial disability; being predisposed to clinically related health problems; and comorbidity from diseases of ageing.
- As a result, carers are providing support for longer and their burden of care is becoming heavier.
- This extended duration of caring means that growing numbers of carers are now elderly themselves, becoming frailer and developing their own care needs, meaning they are less able to provide care.
- The number of people with dementia requiring care is increasing, as more people are living into old age and dementia diagnosis is improving. In addition, more younger people are being diagnosed with dementia.
- The needs of cared-for people and their carers are interdependent. Cared-for people's wellbeing depends on their carer's ability to provide care. In turn, carers' central need is to see adequate services provided to their loved one. Supporting one is supporting both. Supporting carers is not an 'add-on'.

Vulnerable carers and cared-for people have greater and more complex support needs

STAKEHOLDER THEME 3: ESPECIALLY VULNERABLE CARERS

Carers are not a homogenous group, and their needs vary.

- Families on low incomes often face a vicious cycle of fewer resources, poorer health, more caring and worse income. However, work itself (especially for those in non-professional roles) can increase carer stress.
- Young carers risk worse life chances. Female carers have worse service uptake and self-care. Non-family carers can be ignored.
- BAME and LGBT+ people have much historical mistrust of services, leading to later health diagnoses, poorer service use and worse health. LGBT+ carers and cared-for often receive substandard care, and occasionally discrimination and abuse, from service staff. 'Intersectionality' (combined vulnerabilities, e.g. being both BAME and LGBT+) increases risk.
- Some families or faith groups can pressure carers to cope alone. New immigrants may have language difficulties and no close family supports.
- Unidentified carers may not realise their entitlement, or may hide due to shame, finances, or fear of a loved one's removal.
- Carers with mental or physical illness, disability (including LD), frailty or substance misuse are at greater risk.
- Caring for an additional person, or a child, increases the carer's burden.

Carers are more vulnerable to poor health and other negative outcomes because of the support they provide.

- Neglecting self-care (due to lack of time, energy and/or money) puts carers' health at risk.

Carers who support a more vulnerable person(s) face increased pressure and stress.

- Some cared-for people refuse diagnostic assessment, against the wishes of their carer, so are ineligible for services.
- Sudden-onset caring burdens are more stressful (e.g. from acute brain injury or a disabled newborn). Transition points also trigger new gaps and stress (e.g. moving from child to adult to end-of-life services, or from clinical to social care).
- Challenging behaviour increases carers' burdens (e.g. treatment refusal, personality change after head injury, or LD-related aggression). Carers can hide threats or attacks for fear of unhelpful police or services intervention.
- 'Non-normative' caring burdens (e.g. young dementia patients) can leave carers with little true peer support and no specialist support services.

Stakeholders felt that carers would benefit from greater access to equitable, professional mental health support

STAKEHOLDER THEME 4: MENTAL HEALTH SUPPORT

Many stakeholders reported that carers are often distressed and socially isolated. Carers greatly value spaces where they can speak and be heard.

- Face-to-face groups and online forums give carers the opportunity to process feelings of grief, loss, shame, anger, loneliness, despair and being overwhelmed.

Several stakeholders requested improved access to formal mental health services.

- Carers need better access to both counselling and psychiatric services (including Children & Adolescent Mental Health Services).
- Both child and adult carers need provision for immediate access to crisis mental health care.
- Services should be holistic and family-centred.
- Preventive as well as reactive mental health support is needed.

Services should be accessible, supportive and equitable.

- Peer support sessions need to be easier to access place-wise (e.g. via roving 'pop-up' sessions) and time-wise (via evening as well as daytime sessions).
- All carer support staff and environments must be free from stigma and discrimination; care environments should be 'safe spaces' with trustworthy workers.
- Specialist peer groups are needed to build trust and confidence after historic disenfranchisement, inequity and abuse, e.g. for young, LGBT+ and BAME carers.

Clearer and more comprehensive information could improve the experience of carers

STAKEHOLDER THEME 5: INFORMATION SUPPORT

Stakeholders reported that misunderstanding of carers' statutory entitlement is widespread. They wanted clear, accurate, up-to-date, easy-to-get information on entitlements, and also on clinical, legal, home-care and wider issues.

- Information must be easy to access:
 - Available in person, print and online
 - Several central access points, including carer information experts
 - Consistent and comprehensive across all sources
 - Different languages available
 - Widely promoted
 - Always with a 'real person' to talk to for further explanation
 - Information offered repeatedly at different stages in the cared-for person's clinical and care 'journey'
- Clear communication of carers' statutory entitlement is essential, via all channels (including staff).
- It's also essential to cover:
 - Clinical information on the cared-for person's diagnosis, treatment, implications, care needs and future changes
 - Consent, capacity and confidentiality issues, and implications for the carer
 - Sign-posting to housing, benefits, immigration, legal and financial advice
- Carer training courses should be run over several sessions to encourage peer networking.

Stakeholders identified the need for improvements to service coordination, domiciliary care and other practical support

STAKEHOLDER THEME 6: COORDINATION & PRACTICAL SUPPORT

Both carer and service-provider stakeholders reported the need for better coordination between services, to reduce the carer's management burden.

- Schools and services should agree a protocol for handling learning-disabled children with challenging behaviour. Disputes over the conflicting requirements of school attendance versus behaviour-based school exclusion can cause crises for parent carers.
- Carers would greatly value a pre-agreed crisis care protocol to safeguard their cared-for person in emergencies (e.g. if the carer falls seriously ill or dies).

Many stakeholders advised the need for greater domiciliary care provision, with the same care staff, and for flexible time blocks.

- Domiciliary staff need to have more time to encourage the cared-for person to maintain participation in their own care.

Providing personalised healthcare, housing and residential care options would assist personalised care.

- Continued development of 'reasonable adjustments' to assist disabled patients' healthcare access would support both cared-for patients and their carers. After healthcare discharge, specialist community social support would improve outcomes.
- Supplying housing suitable for both cared-for people and carers needing their own care would help those carers cope for longer.
- Residential care suitable for a wide range of clients, not just the elderly, would be valued.

Stakeholders would value professional help with cared-for people whose behaviour is challenging.

- Stakeholders called for the provision of skilled professional intervention, where appropriate, to encourage a non-consenting cared-for person to access healthcare.
- Assertiveness training for carers would help them to manage their loved one's challenging behaviour, reduce stress and improve care outcomes.

Stakeholders felt that carers would benefit from much greater respite provision, with more flexibility

STAKEHOLDER THEME 7: RESPITE

Respite care provision is insufficient, inflexible, unreliable and too hard to get, stakeholders reported.

- Stakeholders universally agreed that respite provision is essential to give the carer rest and time off to see supportive friends and be a 'normal person'.
- Stakeholders also universally agreed that the current respite provision is insufficient. Respite is too hard to obtain and sometimes unreliable.
- Interviewees reported that respite for groups of carers helps build essential peer support networks, both for young carers and adult carers.
- Many stakeholders called for a more diverse respite offer encompassing: short-term home 'sitting service' care; short-term continuous residential care within the cared-for's own home, delivered by the same domiciliary care workers involved in daily home care; as well as residential care in care institutions. Stakeholders also expressed the need for respite breaks which enabled the cared-for, their carer and their whole family to spend relaxing time together in a venue with appropriate supports.
- Several interviewees stated that respite should be available to all types of carers, and not just the desperate.

Carers advocated co-creation of a more generous, responsive, coordinated and better trained service

STAKEHOLDER THEME 8: SERVICE DEVELOPMENT

All stakeholders called for greater provision of statutory support services, which are co-created and personalised.

- All stakeholders advocated extra investment and service improvement, to promote organisational resilience. Carer support levels should be contractually specified and monitored regularly.
- Partnership working (with carers, statutory services, health staff and other stakeholders) would improve service effectiveness.
- 'Personalised care' means resources allocated according to need, not 'one size fits all' (for example, recruitment of more culturally diverse staff, and better interpreter services).

Key staff training needs were identified.

- Carer assessments need to be better, i.e.: timely, clearly announced, face-to-face and comprehensive, with quick feedback and meaningful, beneficial results.
- Better listening skills would facilitate effective care. Carers are experts on their cared-for person – staff should seek and heed their advice.
- LGBT+ care support training from a specialist provider should be implemented, with accreditation promoted to clients. 'Families of choice' must be treated respectfully. The strongest action is needed in cases of discriminatory or abusive staff.
- All staff should have basic clinical knowledge on the common conditions requiring care (e.g. dementia and LD) and the different inputs needed for various carer types (e.g. parent, child, sibling, spouse or friend).

Better referrals and coordination are needed to improve service delivery.

- Carers want more referrals to appropriate services. Support staff want clear, effective, well publicised referral pathways, with an easily contactable colleague to deal with queries. A central carer service coordinator role would improve integrated service delivery.
- Support service access should be allowed as soon as the cared-for person enters the diagnostic process.

Improving carer data collection and data use could help to drive service change and improve outcomes

STAKEHOLDER THEME 9: DATA COLLECTION & DEVELOPMENT

Collection of carer data should be routine, comprehensive and professionally conducted, stakeholders advised. Data should drive relevant research and service improvement.

- Collection of carer data should be mandatory for all service providers.
- A central, standardised carer register is needed, used by all agencies.
- Comprehensive carer demographic and social information is needed (e.g. ethnicity, LGBT+ identity and faith group).
- Data must be collected in a respectful, professional way that instills confidence that it will be used appropriately.
- Carer support service delivery should be monitored, with performance data used to improve services.
- Carers' feedback data should be routinely collected and used to improve services.
- Data-based carer research should be conducted, with the aim of improving carer support and outcomes.

Carers need more support from healthcare organisations, employers and wider society

STAKEHOLDER THEME 10: WIDER DEVELOPMENTS

Southwark carer stakeholders said that further healthcare and employment supports would lighten carers' load, as would greater societal carer support and understanding.

- Expanded GP and hospital support interventions could improve outcomes for both carers and their cared-for patients. GPs, social prescribers and ward-based carer 'champions' could collect carer data, identify hidden carers, give entitlement advice and refer to support services. Healthcare staff could also support carer self-care, including health improvement activities (e.g. walking for exercise).
- Extra support from carers' employers makes a big difference. Flexible hours, discretionary extra carers' leave, workplace carer groups and networks, and support for local community groups (e.g. free publicity or room hire) would all help support and retain expert staff, at little expense. Carer support provisions should be clearly communicated to current and new staff. Exemplar employers should advocate for best practice within their sector. Support for carers returning to employment is also important.
- Carers need their society to value their work more, and to expand voluntary community support. Greater general awareness of cared-for people's clinical conditions, and likely social implications, would promote social inclusion of carers and their loved ones.

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Southwark has at least 25,700 carers, contributing £447m per year, but their health and finances are vulnerable

SUMMARY & KEY FINDINGS: POPULATION & NEEDS

Carer characteristics and needs

- Between 25,700 and 48,100 Southwark residents are estimated to be unpaid carers (i.e. between 12% and 17% of the population); numbers are expected to increase at least 14% over the next 10 years.
- About 35,400 adult Southwark GP patients are estimated to be unpaid carers.
- In 2019, Southwark carers' unpaid contribution was valued at £447m per year. Without this work, social services and the NHS would collapse.
- Over three-quarters of Southwark carers are working age, and over half are female. There are fewer known Asian carers than expected. The proportion of young, middle-aged and older carers is expected to increase.
- Most Southwark carers mainly provide support with personal care.
- Older carers are more likely to work much longer caring hours.
- UK-wide, BAME carers work longer hours and receive less support. Carers most often support a parent or spouse/spouse-equivalent.
- England-wide, the most common support reasons are physical disability, long-standing illness, dementia and other age-related problems; all will become substantially more common in Southwark over the next 10 years.
- Cared-for people are growing in number and surviving longer but with more health issues, so carers' burden and duration of care are growing.
- Southwark carers are less likely to be employed full-time or at all, compared with non-carers. Nationally, carers rely mainly on their wages for income; one-third struggle financially, yet three-quarters of these same carers regularly pay for caring expenses themselves.
- Poor health affects over one in four (27%) Southwark carers (an estimated 7,200 people) – almost twice the level in non-carers (14%); social isolation levels are increasing; and quality of life is not high.

Vulnerable carers

- All carers are at risk. However, women, young carers, those in ill health (or with other extra burdens), unidentified carers, those with more vulnerable cared-for people, carers from poorer families, and carers from BAME, immigrant and LGBT+ communities risk even poorer outcomes than other carers, and need greater support (specialist where available).

Improving the health, social and economic experience of carers requires action in a number of areas

SUMMARY & KEY FINDINGS: SERVICE GAPS & SUPPORT BARRIERS

Local carer services are not adequately meeting Southwark carers' needs.

- Southwark council performs statutory carer assessments, organises carer allowances and respite, and commissions generalist and specialist carer support services from external providers: Southwark Carers, Citizens Advice Southwark, Alzheimer's Society, Together (at Southwark Wellbeing Hub), Contact, CGL (with HYP), Imago and Coram Voice.
- In 2018/19, Southwark Council had about 1490 recorded carers. At least 21,900 extra local carers were estimated to exist, but unknown to council services. Carer numbers known to service providers did not match those known to the council.
- Nationally, more than three-quarters of local authorities have reduced their carer respite funding level in the last year.
- Carer assessments or reviews were conducted for less than half (49%; 736 carers) of known Southwark carers in 2018/19; this was better than UK-wide levels (27%).
- In 2018/19, only a few Southwark carers of adults are believed to have received council-funded, residential respite for their cared-for person.
- The proportion of Southwark carers who are extremely or very satisfied with social services is low (25%) and has fallen by over one-third over the last two years. (However, 60% of respondents are satisfied with social services.)
- Local and national carers report insufficient and dwindling support, service use challenges, and negative impacts on their health, finances and quality of life.
- Reductions in service funding disproportionately affect more vulnerable carers (e.g. poorer families, women, and young, LGBT+, BAME and immigrant carers).
- National and regional research has highlighted cases of discriminatory and abusive behaviour by paid care staff towards unpaid carers and their cared-for person (e.g. due to LGBT+ identity), and some instances of abusive behaviour and homophobic discrimination have also been identified through local engagement with carers and stakeholders.
- Local carer data records appear inconsistent and incomplete.
- Stakeholders emphasised the need for improved mental health support, respite provision, domiciliary care, financial support, information and advice, service coordination, staff training, data recording, and wider societal support.

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The following opportunities to address the unmet needs of Southwark's unpaid carers were identified (1 of 3)

RECOMMENDATIONS & NEXT STEPS

Recommendation	Details	Suggested owner
1. Carers' assessments (including personal budget and respite eligibility criteria, for carers' personal budgets) adhere to best practice guidance and are developed alongside carers.	Southwark Council should review the existing carers' assessment process alongside carers, in order to develop recommendations which ensure that future provision is in line with carers' experience and best practice guidance (e.g. from the Care Act, National Institute for Health and Care Excellence, and Skills for Care) and makes specific reference to at-risk carers and direct provision to carers. Changes should be implemented by December 2020. Changes should ensure that the processes in place: (i) identify and address carer inequalities regarding health, age, gender, gender identity, sexual identity, ethnicity, faith and finance differences; (ii) ensure that harder-to-reach groups have access and 'voice'; and (iii) target more vulnerable carers, based on demographic data.	Adult Social Care
2. Carer mental health support is made more effective.	More carer mental health support is needed. Provision needs to include SLaM and Improving Access to Psychological Therapies (IAPT) programmes. Service commissioners and service providers need to agree quality standards that, wherever possible and appropriate, (i) identify the intended outcomes for carers, and (ii) include carers in service planning and evaluation. Carers fall under the 'complex needs' category of NHS work. Further work by the Joint Commissioning Team is needed.	Joint Commissioning Team
3. Cared-for person support plans are linked across social services and NHS systems	Methods will be considered for (i) interfacing between NHS and ASC systems, and (ii) better use of shared care plans and NHS-ASC co-working, led by Partnership Southwark.	Adult Social Care, Partnership Southwark

The following opportunities to address the unmet needs of Southwark's unpaid carers were identified (2 of 3)

RECOMMENDATIONS & NEXT STEPS

Recommendation	Details	Suggested owner
<p>4. A clear, accurate, accessible, current and comprehensive list of carer support services and referral pathways is compiled, which is made available and promoted to carers via a central point, and which relays consistent messaging from and to all service professionals.</p>	<p>Southwark Council Commissioning and Partnership Commissioning Teams will ensure the delivery of information and messaging through a 'Local Community Offer' (Information and Support Hubs) to support carers, older people and disabled people in Southwark. This will complement the existing work carried out by the Wellbeing Hub. All local hubs and services will share and maintain a 'Southwark Community Resource Directory'. The information delivery process will:</p> <ul style="list-style-type: none"> (i) identify and address carer inequalities around health, age, gender, gender identity, sexual identity, ethnicity, faith and finance differences; (ii) ensure harder-to-reach groups have access and 'voice'; and (iii) target interventions at more vulnerable carers, based on demographic data. 	<p>Partnership Commissioning Teams, Children's & Adults' Services Commissioning</p>
<p>5. Awareness and capacity are built within the Voluntary, Community and Faith Sector, to ensure that opportunities to support carers are identified and that carers are encouraged to utilise available services.</p>	<p>In line with best practice guidance, through the development of community hubs, Southwark commissioning will ensure that community groups, such as faith organisations, are in a position to identify carers and encourage service uptake.</p>	<p>Commissioning, Children's & Adults' Services</p>

The following opportunities to address the unmet needs of Southwark's unpaid carers were identified (3 of 3)

RECOMMENDATIONS & NEXT STEPS

Recommendation	Details	Suggested owner
6. Service design is user-centred and needs-led.	The Carers' Pathway Board should incorporate service users' experiences, feedback and recommendations into future service developments, by: (i) conducting further local research on service user 'journeys' and experiences (including poor carer health (considering sleep, healthcare access and finance) and service access barriers (including cultural beliefs and practices)); and (ii) pursuing best practice in user-centred digital design, and incorporating digital carer support options within service design and development.	Adult Social Care, Commissioning, Children's & Adults' Services
7. Service commissioning is financially sustainable.	Service commissioning should be financially sustainable and guided by local return-on-investment research.	Commissioning, Children's & Adults' Services
8. A clear employment support pathway is developed for carers	A direct link between ASC Community Hubs and Southwark Works (currently contracted to provide carer employment support) is developed and monitored.	Adult Social Care, Commissioning, Children's & Adults' Services

Find out more at
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Knowledge & Intelligence Section
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