

**The Edgware
Road Project**


Possible Studies
Pamphlets

Studies on a Road

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**FOR A
WALK WITH:
DEMENTIA
IN THE CITY**

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Comissioned by the Edgware Road Project

This pamphlet was produced using the online archive and publishing tool edgwareroad.org, created by Bombay based media collective CAMP while in residence on the Edgware Road.

It is part of the series, *Studies on a Road*, in which groups who took part in the Edgware Road Project from 2008–2016, have shared their studies of the area and reflections on the stakes of the project.

The Edgware Road Project was developed in 2008 to support local and international artists and community groups to develop 'possible studies' responding to issues faced by those living, working and visiting the area. Over these 8 years a widening gap of inequality has opened in the area at the hands of local processes of development and the national climate of forced austerity. In response to these conditions, groups that included artists and non-artists were supported in their development of analyses and actions that would address the various dimensions of the development process. Four main thematics have opened up in response to these inequalities outlined in this series. They include Policing, Education, Housing and Care.

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EXITING THE ELEVATOR AN **Amal, yesterday as we went for a walk with the residents, and Phyllis and I were remembering how the *For a Walk With...* project started in 2013. I was talking about an observation I had when entering the care home for the first time. I noticed a gap between the residents and the care workers, made visible through the way they both moved. It seemed to me that the residents sit quite a lot, while the care workers run around all day. In response to this apparent disconnection I proposed to go for a series of walks with the residents and the care workers in order to bridge this gap, and to explore what walking together inside and outside of care home could possibly reveal. PH Yes. We had discussions about the local area and many people were so knowledgeable that we could basically cover about 150 years of the history of the area. That was**

incredible! LAUGHTER AM **That's amazing! And yeah, I mean it's a kind of rethinking about artists or people who do art projects, about how they are able to enter spaces and how people experiencing dementia in residential care can be a part of and at the core of these conversations. PH Indeed. Yesterday we were having a sort of intense political argument in here. LAUGHTER AM About what? AN & PH About care! AN It was about the direct relationship between care work, dementia and redevelopment. AM And? PH Well, it wasn't really an argument you see. After 30 years in residential care, I was talking about how working and living conditions have changed, what it means for the residents, and for the care workers. AM And do you think anything has changed or is changing? PH Well, nursing homes and residential homes are closing down. The council-run homes are getting sold off and the day centres are closed. Also, there is a lack of staff and training, and even more paperwork.**

PASSING BY THE CARE MANAGER

AM **I am asking because this care home, Carlton Dene and the other one you are working in, Westmead got sold off. Right? PH Yes. We're still going through an adventurous five year long privatisation journey; one of the care homes will, at some point, be demolished and the other one, redeveloped.**

How or when exactly, nobody knows. Also, nobody knows exactly what it will mean for the residents and staff. We were talking about it, about how it actually affects all of us. Pretty much everybody is caught up in this shift towards privatisation, precarious working conditions and austerity. And of course, pretty much everyone could potentially end up in residential care sooner or later.

AM I see. Seems a question of agency to me...

AN Yep. And I think focusing on care and privatisation might allow us to think about these processes on many different levels. In particular, I wonder how a nondeficient acknowledgement of dementia could be useful in its alternative understanding of time, space and identity. And how it might allow us to ask how the care home, the city and the state are organised and how we live and work together.

PASSING BY THE LAUNDRY

On the scale of the everyday, going for a walk reveals the different forms of the existing (and absent) networks in the care home and in the neighbourhood. Going for a walk allows space for thinking about the politics of care, as well as the process of redevelopment — both from the position of people receiving care and from the position of people which are directly affected by redevelopment in relation to their working and





living conditions. On another scale, going for a walk with care home residents and care workers proposes a mode of operation, one that allows us to perceive and rethink the processes of privatisation in the city. It challenges the accepted understanding of redevelopment as urban amnesia. Instead of amnesia, dementia seems a far more useful and appropriate way of understanding redevelopment processes. Many of the findings throughout the project point in exactly this direction. ^{PH} Anton. Do not overcomplicate!

^{LAUGHTER} ^{AN} Well, to me it seems that thinking of redevelopment as urban amnesia is a kind of strategic mistake. What is happening to our cities and memory is not an amnesic state caused by an accident, but a gradual erosion of memory — a form of dementia. Living in London often feels like a lot of people already experience many of these symptoms. We can see and feel this in the everyday and over longer periods of time, through the continuous collapse of neurological social and cultural networks. ^{PH} Well, you see Amal, this is the kind of discussion we were having. And whether one agrees or disagrees, there seems no way around this conversation. We have to think about what living in the care home and experiencing dementia and redevelopment actually mean now and also what they will mean in the future. And after going for so many walks over the last three years, it is for this reason we are making this publication.

8 FOR A WALK WITH: ANTON (AN) BETHANY (BE) HELEN (HE) ISRA (IS) PHYLLIS (PH)

TREVOR (TR) VALERIE (VA)

APPROACHING THE PARK ENTRANCE PH **A place can be special because... of memories.** BE **Usually special places have a lot of memories. If a place looks homely, then it's a special place.** AN **What is homely for you Bethany? When do you start thinking of a place as a home?** BE **It's a place you are accustomed to seeing all the time and is comfortable. In London it's Westminster for me.** VA **I like to walk all around Westminster. I walk quite a lot. I just go walking and walk and walk. I want to walk more outside but, I better go home now and see my Mum and Dad.** PH **Stay with us Valerie. We are in Westminster, and Bethany is telling us about her special places here.** HE **Bethany. Like the place you used to work in Portobello Road?** BE **Hm, don't remember.** PH **Bethany. You used to work in Marks & Spencer a long time ago, right?** BE **Oh yes. That's right, I did.**

TR **There is a pound shop there now, I think.** IS **Right, where the Woolworths was.** PH **Hmm. I think there is a Tesco now.** VA **I can show you. This way.** PH **Where are you going Valerie?** VA **Westminster.**

BETHANY LOOKING AROUND

BE **Now I am lost.**

Where am I? AN **No, I think you're somehow bringing it to the point Bethany. This is how I often feel when I think of the special places I have had. When I go somewhere after a long period of time, all of a sudden you just do not know where you are or what's going on. It happens all the time when buildings get demolished; or new buildings are built; a store has to close; or people have to move somewhere else. It completely changes the area, again and again. In Westminster it is like this every other day.**

BE **That's right, but I mean it literally, it's because of my dementia as well. It gets you. I mean it literally, where am I?** AN **You are in Westminster in London, and we just have left the care home where you live, next to the Westway. We are going for a walk together, just over the road from the Meanwhile Gardens.** VA **I'm not sure, but I think it might be in this direction. I think I'd better go and visit my mum and dad.**

DEMENTIA

AND THE CITY

Walking suggests a process with its own temporality, which can only be experienced through the act of walking itself and neither in text nor in image. It is important to emphasise here that this publication does not aim to detail the outcomes of *For a Walk With...* or to merely depict the walks that took place with the residents of care homes, care workers and neighbours in north Westminster (2013 — ongoing). Instead, through examining walking as a method this publication points towards the diverse states and processes which define the context of *For a Walk With...*, namely dementia, residential care and redevelopment.

***For a Walk With...* can be seen as a vehicle for research that connects acting together with visual and textual dimensions. It offers a lens through which**

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the experiences of dementia, the politics of care and the processes of urban redevelopment can be viewed from the residential care home. The project reflects an intentionally ambiguous approach to contemporary artistic practice, with its own usefulness, form and aesthetics that seemingly escape current modes of institutional representation.

It is worth mentioning that while the diagnosis of dementia rightly points towards a severe condition, *For a Walk With...* aims to contribute a positive acknowledgement of the disease, derived from and driven by the competence of people living with dementia and their carers. The emphasis on the abilities and insights of people living with dementia, with their alternative understandings of time, space and identity can offer a useful strategy to rethink the social, medical and juridical treatments that exclude people living with dementia from making their own life decisions.

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On the surface it might appear common knowledge that the organisation of our cities can be disorienting, unwelcoming and potentially dangerous for a person living with dementia. Instead of taking social and political forms of organisation for granted,

'IN AN OLDER AGE YOU DO NOT WANT TO MANOEUVRE BETWEEN ALL





an inclusive and competence-oriented approach to working together with care home residents offers a unique chance to rethink, reveal and review the social and political processes that lead to exclusion and marginalisation. Yet in order to do so, it is crucial to have an insight into the medical understanding of memory and dementia.

As an umbrella term, dementia can be defined as an irreversible brain disorder that affects different parts of the brain and impacts on a range of functions.¹ The symptoms of dementia often overlap with the symptoms of confusional states and depression, such as: lack of motivation and appetite; sleep disruption; memory problems; difficulty concentrating; fluctuating consciousness; language disturbance; disorientation or seeing things differently.² In 2013, it was estimated that 35 million people worldwide live with dementia. The number of people experiencing dementia is estimated to reach 135 million people worldwide by 2050, and to rise to above one million in the United Kingdom within ten years.³

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Conversations about memory and dementia prompt questions around different forms of networks — from the social networks within care homes and the neighbourhood to the neurological networks in our brains. Interest in the correlation between memory and place in the processes of social and demographic change has grown since the 1970s. During this time,

demolition of industrial buildings and the displacement of individuals and communities has become increasingly understood as a form of urban amnesia. The phrase *urban amnesia* equates the disappearance of buildings to the disappearance of the city's complex memory cells.⁴

The industry-influenced effort by governments and urban planners to revive dying economies through the redevelopment of locations into newly commercial sites often displaces less privileged people. The loss of historic buildings is accompanied by a process of redevelopment that attempts to rebrand an area and results in an experience of a loss of habitat.⁵ **This experience of loss is often referred to as an amnesiac present. In contrast, walking as a collaborative research method — a method that brings care home residents and workers together — provides the tools for rethinking certain processes of redevelopment that place an emphasis on some of the key differences between amnesia and dementia.**

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Amnesia mostly affects young adults and commonly represents a loss of memory of important and recent events brought on by trauma or accident.⁶ **In this regard, thinking of redevelopment as amnesia configures it as a potentially temporary state and a curable condition. It is crucial the process of redevelopment is not understood as accidental, but as a systematic strategy combining the visions and**

actions of governmental and industrial agencies. The current state of redevelopment in London exposes the limitations of the amnesia metaphor. Reading redevelopment through dementia emphasises redevelopment as an ever expanding, increasingly mature and incurable process, a reading that better reflects the complex erosion of memory cells that are taking place in the city.

The latter perspective seems to be more constructive, and suggests modes of operation to deal with the processes and the symptoms of redevelopment. In doing so it is important to emphasise a positive outline of dementia and to consider the care home as a point of departure for reading the city. In this way, walking in the context of residential care can be seen as both a proposition providing the means to rethink current understandings of urban redevelopment and as an active response addressing issues surrounding the politics of care, memory and redevelopment.

18 FOR A WALK WITH: ANTON (AN) CHARLES (CH) GRAHAME (GR) JEAN (JE)





THIS IS A COLLEGE,
IS IT?

MARIA (MA) PHYLLIS (PH)

WHILE PREPARING FOR THE WALK JE **We'll go together. Start downstairs and I'll show you around.** CH **This is a college, is it?** AN **This here?** CH **Yes.** MA **It's a care home, not a college. But I am sure we can learn as much here as we would learn from a college.**

APPROACHING ENTRANCE TOGETHER

So. Let me start. My name is Maria and I work here. This is the entrance to the care home. When you arrive, you usually come through this door. Charles, I will give you another introduction today because you are still new to the house. JE **Okay. Good if we don't go outside today. It's wet and cold.** MA **Grahame will also join us. Have you been here before Grahame, do you remember me?**

GR Sure. I live here. We are all living in this place. It is not very big. Just a little place. And what it can give us. We will take it.

CH Who are these people again? MA Other residents like you, but who have been living here a little bit longer. I will show you around, but first we have to get to the lift. JE I like it here. This place, they have everything. Also my own people work here. People from Nigeria. They're good for any problem. There are even people from Abeokuta, where I am from. AN Jean. When you first moved in, what was the first thing you needed to know? JE I think it was the routine. What time is breakfast, dinner and supper. I wanted to meet our star chef. PH Charles, look the staff have the same uniform and their names are written on the card. Grahame, do you know the names of the staff? POINTING TO NAME-TAG GR Only some of them. MA We are going upstairs. This is where your bedroom is and where you live. You ready?

MOUNTING STAIRS

JE I'm living here too.

MA Jean, I remember the first day you came in.

JE Are you sure? You know me? MA Yes. Your surname is Kaudoulodu and we often call you Ou the way you like it. JE Yes. It's true. MA Jean, you were fairly settled when you first came in and your daughter

comes to visit and brings snacks. You never seemed traumatised and always seem alright staying after everybody had left. AN And how many people are traumatised? MA Well. I would say 90 percent of residents miss home, in one or way or another. They're sometimes just told that they are going on holidays and that this place is a hotel. So some of them will ask where the porter is and things like this, and what hotel is this and things like that. Some people are comfortable knowing about their dementia but for others it can be really hard. JE Well, I know that it's my condition, that is why I am here, but it's getting better!

TURNING INTO A CORRIDOR

MA Some residents take a long time to settle. You think they're settled but sometimes people just start walking and want to go home. Even if we are able to settle them for a day it might repeat again the next day. We are also always asking their families to bring personal items from home to put in their rooms to create a more familiar environment. AN It seems that one can walk around the whole house in a circle, in sort of a loop. MA Yes. Because some people who experience dementia sometimes stand up and need to walk somewhere. And even though you cannot leave the house, you can walk yourself out until you are tired and then rest.

We have good staff here; it's only that everybody is pretty busy. ^{CH} **And what training do you have?**

^{MA} **Great that you're asking, many residents do too. I am a certified care worker with over 15 years of experience and I have worked for over ten years in this particular care home.**

I feel really good when care workers and residents get familiar. Even if you go on holidays and come back you hear sometimes: *Oh we missed you and where have you been?!* It's so important to have familiar faces and to know who is here doing what.

^{AN} **I was also wondering because we have been working with Phyllis for a long time and we've noticed that the training for staff has changed quite a lot and now you are doing it online.** ^{MA} **Yes. It's all changing now. Instead of learning together with the managers and residents you just click your answers at home.**

You can also come back to each question until you have 100 percent. In that it is both impossible to fail and at the same time, it is impossible to learn anything about care. Plus we have to do it after work

and it's unpaid. After 15 years working in care I wonder how someone new would learn to even push a wheelchair properly. I am not even talking about how to support and communicate with residents throughout their time living in here. You can't learn any of this online. ^{GR} **You are good in taking care sweetheart.**

LAUGHING

^{MA} **I think communication is key and it's often so underestimated in training. It's so important if you do not understand... not even**

what people say, to understand their actions and body language. Some of the residents can't construct a sentence or select the words so you have to know their body language as well. To know the difference between whether the person feels sad and lonely or just wants to go to the toilet for instance. Some people forget their second or third language and can only communicate in their mother tongue. ^{PH} **We have so many brilliant care workers who are really good at that.**

^{MA} **Let's turn right here, Charles. We're almost there now.** ^{CH} **That's good. I feel a bit tired and would like to lie down.**

PASSING A LONG ROW OF CHAIRS

^{MA} **Well, to what Phyllis is saying, I think there are always so many sides to it and ways to improve it. We also have to make the time to spend with residents in many different ways. Through more staff but also each one of us here can organise a little bit better sometimes. Because otherwise people feel neglected if you don't make the time. I know we take care of the bedrooms and laundry and other things but that has to take second place to what people who live here want. Residents must be the most important in the care home.**

MA And when you talk about walking together Anton. Obviously we need more time. With more time we could run less and residents would sit less. They could walk more, like we are doing now, whether it's inside the care home or outside in the neighbourhood. There should be a way to meet in the middle. At the moment we only have two people on the unit, so if we wanted to go out with a resident, even for a cup of coffee, it would only leave one member of staff on the unit. But yes, I think to get more staff, we would really need a strong case.

AN What do you think would be a strong case? MA ...

PH Charles. You see.

We have arrived. This is your room. You can rest yourself now if you like. CH Is it really mine? PH Yes, look, all these pictures of you and your family and this is your Member Of British Empire certificate in the frame. CH Oh, I see! True. I better have some rest now. Can I have a cup of tea? MA Of course, Charles. I'll bring it to you in a minute.





'IT IS THE SAME PLACE AND AT THE SAME TIME IT IS REALLY NOT...' 29

special places

COMFORTABLE
ACCUSTOMED
SETTLE
ROUTINE
FAMILIAR
HOMELY
HOME
LIVING

LAUNDRY
BEDROOM
ROOMS
TOILET

UPSTAIRS
PERSONAL ITEMS
PICTURES
MUM AND DAD

HOTEL
KNOWING
WHERE AM I?
GETTING BETTER

LOST
LOOP

CHEF
WORKING
WORKERS
WORK

CARE WORK
GAP
UNKNOWING

RUN LESS
GOOD STAFF
MAKE THE TIME
ORGANISE

UNPAID
UNPAID
IMPOSSIBLE TO
CERTIFIED
ONLINE

dementia

NEUROLOGICAL
NETWORKS
CONTINUOUS COLLAPSE
SOCIAL
CULTURAL
FORGET
MIND

COMMUNICATE

RESIDENTS

PRECARIOUS
HOW WE LIVE AND WORK TOGETHER
PRIORITIES

WORK

LONDON

MEANWHILE GARDENS
WESTMINSTER

the city

WESTWAY
WESTMINSTER

DISCONNECTIONS

NEUROLOGICAL
NETWORKS
CONTINUOUS COLLAPSE
SOCIAL
CULTURAL

**memory.
architecture.
autonomy.**

ATTENTION
EFFICIENT
MEDICAL SERVICES
CUP OF TEA

REBUILD

DEMOLISH
REDEVELOPERS

CHANGES

MARKS & SPENCER
PORTOBELLO ROAD
WOOLWORTHS

TESCO

WORK

HISTORY
FUTURE
NOW

STATE
BUDGET
CUT

AUSTERITY

ELECTION
**dementia
in the city**

**dementia
as a method**

care

LIVING CONDITIONS
CARE HOME
POLITICS OF CARE

STAFF
UNIFORM

PROVIDER

UNDERESTIMATED
TAKEN SERIOUSLY
INVALUABLE

PRIVATISING

SOLD OFF
CLOSING

COMPETE
COMPETITION
PRIVATISATION

BUILDING
GRADUALLY DEVELOPING

INSIDE

**this is a college,
is it?**

redevelopment

**dementia
in the city**

INSIDE

OUTSIDE

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MEMORY.
ARCHITECTURE.
AUTONOMY.

Walking together with residents from the care home was the starting point for an investigation into the relationship between memory and architecture. In architectural theory, memory of place is referred to as an experience of exchange; a relationship which constitutes the most significant externalisation of human memory.⁷ This perspective allows us to analyse buildings as forms of storage for memory and time. On a micro level, one building can be compared with a complex cell, while whole neighbourhoods and cities can be viewed as complex assemblages of cells, in constant dialogue with each other.

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Increasingly, the populations of cities are excluded from decision-making processes of redevelopment. Parallels can be drawn to the experience of care home residents who are largely excluded from making decisions about their living conditions, due in part,

to the medical diagnosis of dementia. It can be said that the process of redevelopment directly influences the ability of people to communicate, remember, imagine and construct their future. The loss of memory through the erosion of neurological networks that characterises dementia is mirrored in the loss of social networks, isolation, and the need to be taken care of in the residential care home. In this sense, memory exceeds the processes of the brain through all our senses and organs, which think, remember, experience and exchange with space.

Translated into architecture, memory and walking bring the capacity to network and to remember in relation with the autonomy of a person living with dementia.⁸ Especially with regard to isolated communities of care, in which walking is viewed, not only as a leisure activity, but also as an issue of mobility. The act of walking proposes a dynamic process of creating spatial and social networks while engaging with space and the people inhabiting it. As a person's dementia progresses and mobility decreases, establishing networks within the care home and in the neighbourhood becomes increasingly more challenging as a result of the collapse of neurological and social networks. This inherently positions autonomy as an ethical approach concerning memory.⁹ The autonomy of a care home resident can be defined as a right to agree or disagree with his or her treatment. While current developments in care

for people living with dementia in residential care emphasise personal autonomy, this is contradicted by the resident's perceived inability to contest medical treatment.¹⁰

Traditional approaches to the development of social networks inside and outside the residential care home create a challenge and establish a paradox. This paradox emphasises a reciprocal and self-excluding relationship, in which the residents as recipients of the care work, are warranted their autonomy and independence, while the symptoms of dementia, memory, and identity loss are understood as an incapability of developing autonomy. With respect to medical treatment it speaks to an assumption about residents' competence or incompetence.¹¹ Differentiating between the two in the judgment over one's decision-making capabilities can either involve the resident in making a decision or ignore their wishes and preferences.

Walking in this context proposes an alternative. It is a powerful tool to address memory in relation to autonomy and a means to re-establish social networks and build collaborative relationships. In this context the either / or relationship and the paradox outlined above (involving / ignoring the resident; competence / incompetence of the resident) can be counterbalanced through a neither / nor relationship inherent in the process of going for a walk.

Here, walking can be understood as an activity with its own temporality. It can be experienced as a process and a state of being in between the coordinates of A and of B — not yet at B and no longer at A. Being neither at A nor B suggests a continuous transition and a place from which we may derive understanding of the possibilities and restrictions of space and develop autonomy through dementia. In order to do so, it remains important to incorporate the multitudinous symptoms and conditions of dementia as a driving force, rather than a barrier, within the process.

This context of indeterminacy provokes the question of how dementia and walking can provide tools that address political issues of redevelopment and the organisation of space inside and outside of the care homes. More specifically, *For a Walk With...* asks how emancipatory political processes and autonomy can be developed from within the care home itself rather than being imposed on it by exterior political agendas.

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'I USED TO TURN INTO THIS STREET AND

IT WAS QUIET. YOU DO NOT SEE MANY STREETS LIKE THIS ANYMORE.'

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40 FOR A WALK WITH:





REDEVELOPMENT

ANTON (AN) IBRAHIM (IB) PHYLLIS (PH) REBECCA (RE)

LOOKING ACROSS KILBURN PARK ROAD AT GLOUCESTER HOUSE PH **I wonder where all the people have gone?** AN **Maybe not all of them are gone.** PH **Well, not all of them but most. They have to go anyway because they will knock it down. It's hard.** RE **I don't know, 'cos we were told, that they will demolish our care home, rebuild and then we would be the next one, but we don't know.** PH **Well. The idea is that they want to bring different types of care under one roof in a big building. I think it's a good thing. It would be us on one floor, another care home on the other floor, other medical services on another floor and so on. Everything would be so close and more efficient.** AN **And what would it mean for the workers, less staff all together?** RE **Well it's hard to tell, we know as much as the residents.** AN **So far from what I understand this government will cut the budget again and**

is even considering the idea of privatising care homes. Meanwhile, with the private providers it's clear that they need to compete with each other and this also means not only *cuts cuts cuts*, but also that the attention and priorities of a private provider can also be directed towards a competition outside of the care home and not towards priorities inside of it.

^{IB} You saw it during the election also. It's a big theme. Because everybody needs to come to power. Again. So they have to give bribes to the people. You understand? Like with the budget for care, they won't cut this budget now, but when they come to power after the following budget they will say, we need money, we will cut. Same with care. Cut and privatise. During the election though, when everybody is in a difficult time and politicians need support and they try to bribe people in different ways — transport, care, many different ways.

SLOWLY CROSSING THE ROAD

Like for instance, I live here. I get all this mail saying things and promising a better life in the future and so on, but between the lines they just let me know what is about to happen, whether I want it or not. And imagine I say, I do not want to move. What do you think will happen? ^{PH} You get letters all the time, then

a new company or redevelopers come and introduce themselves, maybe have one meeting and then by the next time they send people in, you are already with a different provider. ^{AN} After you got privatised the inside look of the care home changed, you got uniforms, the dynamics have changed somehow. It seemed to me that the same body had got a very different mind all of a sudden, as so many things got replaced from the inside. ^{PH} Strangely enough, as these changes were happening many residents started to fall repeatedly. It has ceased now but, for a while, this change was accompanied by the repeated falling of some residents. ^{IB} It always feels the same, if you like it or not, you are expected to accept it and if not, just to move to the other home. ^{PH} Yes, the message one gets is usually very simple. What it means in terms of living and work is relatively a new thing though and I see it gradually developing over the last 30 years. To me this really is new, whether you work or live in a care home, what really counts equally for workers and residents is the unknown, that you really can not know about keeping the job or your accommodation.

RINGING ENTRANCE DOORBELL

We don't even talk about being underpaid and that you don't go into this job expecting to be rich. There are so many aspects of care, like what *to care* actually means, and some of these aspects are so invaluable. That I am again and again so surprised about how this is often not being taken seriously. Especially considering that we all might develop dementia and move into a care home at some point.





DEMENTIA

AS A METHOD

Analysis of participation in residential care homes in the United Kingdom indicates that the care homes remain isolated communities of care, spaces in which older people are not only excluded from taking part in the research on their own living conditions and end-of-life care but, are also, increasingly dependent on proxy accounts and the views of others or after-death-analysis based on notes and medical records.¹²

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Despite many attempts to counter-balance current tendencies surrounding the politics of care, the treatment of care home residents and care work points towards an on-going political process of exclusion and marginalisation. Nevertheless, a constructive re-evaluation of the processes at stake, one that places an emphasis on inclusive,

competence-oriented and bottom-up approaches to practice within care homes, poses a question of how dementia can also be approached positively. It does so by proposing practical tools for reading the politics of care on a smaller scale and re-reading the city and memory on a wider scale. This re-evaluation requires a closer consideration, in which dementia can be understood both literally and as a metaphor for political agencies, for memory and the organisation of the city.

Thinking about memory in relation to forms of social organisation is a study of the political and technological apparatus of memory outside the brain.¹³ Architectural theory outlines the relationship between memory and place through the built structures within the city.¹⁴ City buildings contain and project memories, articulate spaces and can be seen as external memory devices necessary to grasp a continuum of culture and tradition.

In oscillating between literal and metaphorical medical conditions, the experience and potential of dementia can be outlined as a useful analogy for redevelopment in the city. In utilising *For a Walk With...* as a research tool with walking at its core as a tool of enquiry, this complexity of social and political processes at stake can be addressed through Susan Sontag's concept of *illness as metaphor* and Hannah Arendt's concept of *remembrance*, which

outline a particular approach to political action through the tense space of creativity in between formal and informal practices.

In her books *Illness as Metaphor*, and *AIDS and Its Metaphors*, Susan Sontag investigates a particular understanding of illness as a metaphor to incorporate the patient within authoritarian rule and state sponsored repression and violence. Describing the stigmatisation of the ill through military understandings of illness and the military phrase *total war*, Sontag concludes *we are not being invaded. The body is not a battlefield. The ill are neither unavoidable casualties nor the enemy. Deriving from this metaphorical understanding of illness, Sontag suggests we: Give it back to the war-makers.*¹⁵

While Sontag elaborates processes of exclusion in relation to patients with Cancer and AIDS, the processes surrounding dementia also emphasise marginalisation and exclusion of underprivileged and ill. In this regard, inclusion of the care home residents in decision-making processes requires a method in which dementia plays a central role. Consequently, developing Sontag's proposal to give it back to the authoritarian violence and repression, one could consider using dementia as a means for reading the city so as to employ the practical potential of dementia as a metaphor and analogy for redevelopment.

In the context of dementia, *giving it back* suggests taking action as a practice of emancipation and freedom in relation to memory. In this regard, Arendt's concept of remembrance can be useful as it distinguishes emancipatory action through five important features: unpredictability; boundlessness; irreversibility; irreducibility to law-like descriptions; and the capacity to create *new beginnings* that Arendt equates with human freedom.¹⁶ In relating this form of action through the concept of remembrance, Arendt emphasises a specific way in which political thinking functions as a bulwark against the tides of time that might otherwise erode our sense of hope and purpose. Arendt extols remembering not in order to turn back but rather as a form of action in the face of an unknown and unpredictable future.¹⁷ According to Arendt, remembering is a form of political action that proposes a space for creativity. Creative acts can define the conditions for constituting a political world. Here, the tensions between creativity and the political are exposed through acts of conformity and rationality embodied in *common sense*.¹⁸

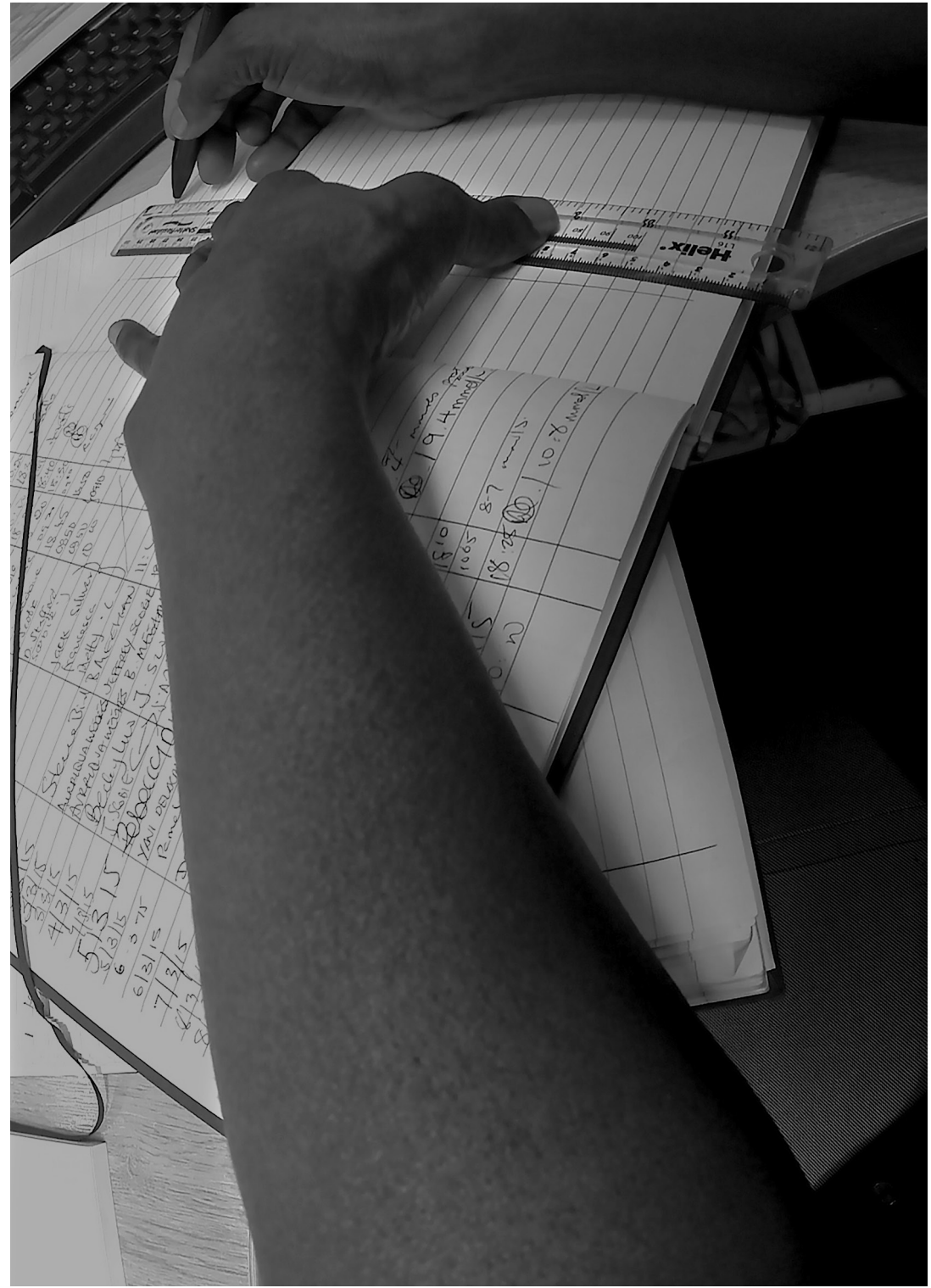
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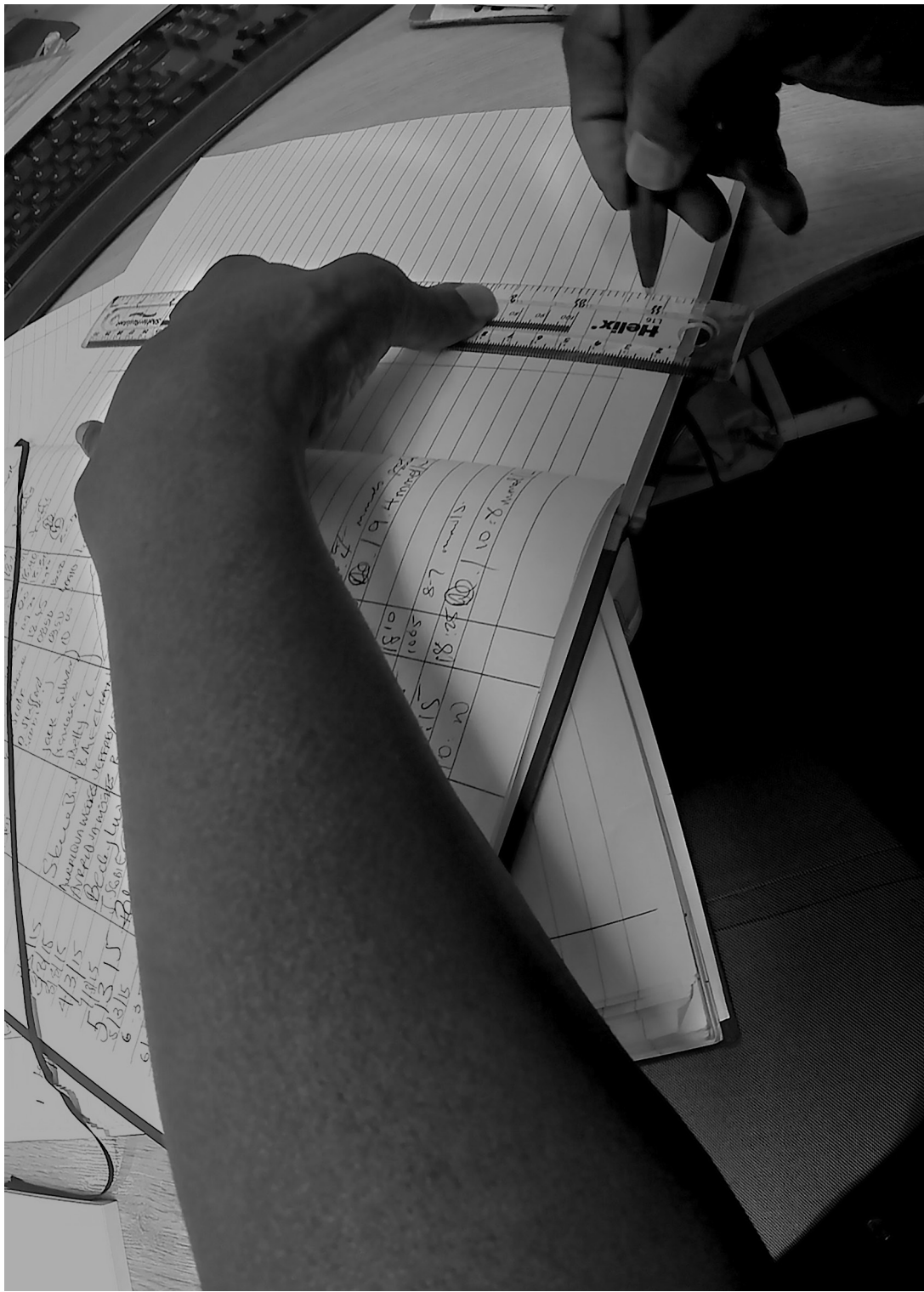
The perspectives of Sontag and Arendt offer an orientation towards dementia and the city, as they carry potential to reinforce emancipatory practices in the context of the isolated communities of care and in relation to redevelopment. Both address a future oriented space that allows us to re-think dementia as a useful method collaboratively addressing conditions

of isolation and marginalisation, with the residents of the care home at the core of the process. The practice of walking in this context can also be useful in reconsidering care homes as a place of new beginnings and addressing how we work and live together. Although walking together can be seen as an activity that escapes forms of representation, it nevertheless proposes a material presence of events and persons that can be remembered in the public space. This form of presence can be seen as a process to negotiate social power structures and indicate which groups have succeeded in entrenching their individual conception of history as a valid and binding particular memory of a neighbourhood.¹⁹ Dementia as a method in this context can provide perhaps a less optimistic, yet more practical and pragmatic perspective, to address both politics of care and the processes of redevelopment.

Finally, it can be said that the positive acknowledgement of dementia in its alternative understanding of time, space and identity carries enormous potential in providing a useful method to address diversity of states and processes such as living and aging in a city, from which we might not be able to walk away from so easily.

54 'I THINK THE OLDER YOU GET, THE MORE EXCLUSIVE THE NEIGHBOURHOOD BECOMES.'





'WHAT IS THE PROCESS, WHO PROCESSES WHAT, TO WHOM, AND BY WHAT MEANS IS IT BEING DONE?' 57

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IMAGES

The images in this publication are stills from the film *For a Walk With...* developed together with the residents and care workers of *Carlton Dene* and *Westmead Elderly Resource Centres* between March 2014 and March 2015.

FOR A WALK WITH

For a Walk With... is a proposition to work with residents of care homes experiencing dementia and with care workers in context of residential care. It uses the act of walking as a point of departure in order to address issues surrounding dementia, the politics of care, redevelopment, city and memory. Initiated by Anton Kats in 2013 *For a Walk With...* is situated in *Carlton Dene* and *Westmead Elderly Resource Centres* in London and explores walking as a useful method to investigate and collaboratively respond to the site-specific problems in the everyday.

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THE AUTHOR

Anton Kats (b.1983, *Ukraine*) is an artist, musician and dancer based in London. Anton's practice derives from informal everyday relationships within a vibrant neighbourhood in Kherson, Ukraine and is complemented through necessity and pragmatics of self-legalisation in Europe via entering formal institutions of education. After attending masters programmes in *Art in Context* at the *University of Arts Berlin* and *Interactive Media: Critical Theory and Practice* at *Goldsmiths College*, Kats continues his studies through a practice-based doctoral research at *Goldsmiths, University of London*. Developing practice-driven research projects, Kats explores the ambiguity of art practice as a question of agency and intentionality and develops site-specific work engaging with structures of self-organisation, self-education, marginalised people and the non-normative. His enquiry reveals the diverse forms of learning necessary to generate critical and practical knowledge in the everyday and combines pedagogy and art practice as a form of investigation. Kats's goal is to explore the potential of collaboration within formal and informal social structures and to jointly develop useful methods that enable to independently take action. Kats is an editor of *Sound Space Downtown: Workbook and User Manual*. His works have been exhibited and performed in venues including the *Serpentine Galleries*, *Tate Britain*, *Victoria and Albert Museum* and *The Showroom Gallery*.

PLEASE NOTE

The names of the residents and care workers have been changed in deference to the complexity of legal permission frameworks, the lack of autonomy experienced by people living with dementia in residential care and the precarious notion of care work.

The *Studies on a Road* pamphlet series was produced using edgwareroad.org

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The Possible Studies imprint was developed through the Edgware Road Project. Initiated by Serpentine Galleries in 2008 the Edgware Road Project links local groups and international artists with people living and working in this area. The itinerant project base for the project is the Centre for Possible Studies, home to screenings, events, a publishing imprint and an ongoing project archive.

From 2016 the Possible Studies imprint will be housed at Church Street Library on a specially commissioned shelf dedicated to the local area. Designed by Bahbak Hashemi-Nezhad.

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