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## RECORDS ACCESS CAMPAIGN: OVERVIEW

#### Who are we?

We are a group of Who Cares? Scotland members with Care Experience who are passionate about creating change to how care records are accessed and written. We are working to make change on a national level to the systems and processes which enable Care Experienced people to view their records but also want to raise awareness on the importance of records to those who are or have been in care.

#### Lived experience of accessing records

There are many individual stories of accessing records and although they are each unique, there are common threads which show the power of records and the importance of the access process to Care Experienced people. The personal stories throughout this report have been shared to give a more indepth insight into what it can be like to access your records. It is important that professionals and those working to improve and create new systems for accessing records about Care Experienced people, ensure that the lived experience of those people are central to shaping and influencing the design and implementation of any changes.

#### What can accessing records be like for Care Experienced people?

We have spoken about some of the barriers, challenges and difficulties for Care Experienced people accessing their information.

#### For example:

- The Subject Access Request process is seen as a bureaucratic, uncaring process, in which a person can be bounced between local authorities.
- There is a lack of trauma-informed practice, it often feels "transactional".
- There can be charges for accessing records (principle, extent, repeated for each inquiry).
- Records can also be lost, incomplete or they are often out of order. This can be made worse by them being illegible and difficult to read.
- Sometimes there can be risk-averse attitudes shown to Care Experienced people requesting information, with questions such as "why do you want them?" and "what will you do with them?" being asked by those holding the records.
- Redaction is often disproportionate and can often seem extreme. OneCare
   Experienced campaigner commented that "my own handwriting was redacted."

#### What can reading care records feel like?

The content of records can be extremely difficult to understand and make sense of, adding confusing new information or providing conflicting perspectives on life stories, timelines and how specific events occurred. It can be distressing to read how professionals have spoken about a Care Experienced person and the people important to them in their files and judgemental comments can be extremely upsetting. There can be inappropriate supervision enforced, in which a person can only read their records in a social work office with a professional standing over them. There is support that is needed which is currently lacking,

but it must be focused on how to make sense of records and be tailored to what the Care Experienced person needs – or doesn't need.

#### ALICE'S STORY

I am 20 years old. I went into care when I was 15 and left when I was 18.

I decided to access my care records in a sense because I "wanted to know where I came from" but also because I thought I had been lied to and not told the whole truth about what happened to me.

I've always kept everything from when I was in care. So it made sense to get my care records too. At first it was difficult because no one told me where I could get them. I had to ask a lot of people before I found out I could do an online application. Once I knew where to get them, it was a simple correspondence. I was also quite pleased with the how nothing was left out of the document.

When I did get them it took a very long time to read. Nobody provided me with support regarding specific documents. I learnt a lot of things I possibly shouldn't have known and a lot of my family's secrets were exposed. I felt as though I had been betrayed by a lot of people and organisations.

I think that there should be somewhere which clearly states where I could get access to my records and this should be the same for anyone else. I also think there should be an organisation or someone to support me with this. I also think that the person dealing with my records should know me and understand how much they should know e.g. what they can mentally cope with. I think when looking for records we should get support after or there could be someone to ask me if I want someone to go through the documents with them.

## WHY ARE RECORDS IMPORTANT?

Personal information in records is viewed in legislation as "data", however, we want it to be acknowledged as more than this. Records about someone's life are key to them understanding life narrative, creating integrity of experience, building self-esteem and can also have the power to create new meanings for life events.

It has been shared multiple times by our members that being in care can be connected with a lack of memories, or at least clear memories, which help shape how you view what happened in your life, why it happened and when. We strongly believe that accessing records can be part of a journey to finding out who you were when you were younger.

Therefore, it is important to make clear that the purpose of records are not only to evidence what has happened, in a way which serves the needs of the sector and professionals working around an individual, but also to create a narrative for that individual. Our aim is that the current practice of recording information about a child or young person in care, is influenced by this shift in purpose. We want to see records which are designed to be viewed in future or at the time they are created, by the very individuals being written about.

#### **ALICIA'S STORY**

I remember the day that I received all of my care records; all eleven years of them. I wasn't in when the postman had delivered them, so I had to go to the post office to collect them. I got handed two huge envelopes that better resembled large bags, and they had 1 and 2 written on them. Have you ever held the equivalent of your life in your hands before? It's a really weird feeling.

I was considered 'looked after' under state supervision at the age of six and was referred to aftercare services at the age of 17, which means that I was in care for eleven years. I was Looked After at Home, where I was living with my biological birth parents but had a compulsory supervision order, and I was also in Kinship care with my grandparents for a bit. Both of these types of care are often overlooked and not considered as types of care. I



think this happens because there isn't necessarily a narrative for us. Being 'in care' is usually categorised under either being in residential care or living with a foster family, but for those that are still living at home or formally with friends/relatives, it sets us aside and can often give us a broken sense of identity.



I decided to file a subject access request to my local authority because I too had a broken sense of identity. I had spent most of my childhood looking after my mother who was a severe alcoholic. Most of my friends at school were busy going on playdates, spending quality time with their family, and going on holidays – this was not the norm for me. I was used to being a carer, and that was my priority. I didn't really have a sense of self until I was around 14. I wanted to know if there was any information about me as a child that I couldn't remember. I knew that the only way to access this would be through receiving my care records.

On the **23<sup>rd</sup> March 2018** (almost exactly a year ago), I filled out an online application form to the Council to receive my

care records. **3 days later** they sent me an email of acknowledgement to my request, and that they had a statutory obligation of **40 days** to process my request.

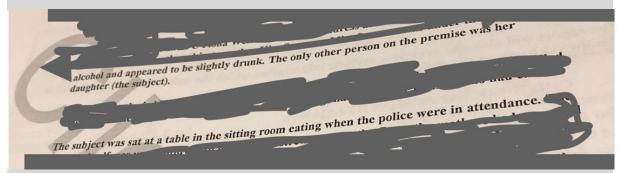
I wrote an email on the **13<sup>th</sup> June 2018** asking for an update on my request as I still hadn't heard anything, and it was a month past the statutory timescale that they had given. I received an email an hour later stating that it was taking so long because my files needed to be redacted. They explained that they were extremely busy and that they would try to get my files to me as soon as they could.

With support from my Barnardo's aftercare worker, I sent another email on the **19<sup>th</sup> July 2018** asking for another follow up. Again, they were very quick to reply to my email and replied the day after saying they had a very large volume of requests and only two people worked in this specific department. They said they refused to give me another timescale

because they could not promise to keep to it, and that they recommended me to contact the UK Information Commissioner's Office (ICO) and write a formal complaint. I found it alarming that somebody working in the council had recommended me to do this, which made me think that my situation was not the minority, and that lots of people probably experience the same dishonesty and inadequate response towards the request of their records.

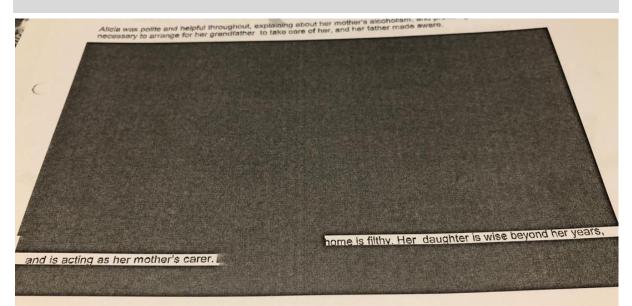
I decided that I would call the Information Rights team in my local authority before filing a formal complaint through the ICO. My Barnardo's worker and I contacted the team and were put on hold for around an hour before being called back. The member of staff spoke to me like I was a complete nuisance and told me that it would be unfair to prioritise my request over the 60 other requests that they were dealing with. I tried to explain that these files were very important to me and they contained really important information about my childhood, but she couldn't have seemed less bothered. She recommended again that I contact the ICO and I assured her that I would, as this was the only option that I had left. I was angry at the time, but I understand now that she was only doing her job - just a little less considerately than she could have.

After I contacted the ICO, I received a letter from my local authority apologising for the delay in my files. They said that this is a common issue and that they wish there was more that they could do to eradicate these time constraints. I received my files on the **19th November 2018** and I sat up in my bed until 3am reading details of my life on these pieces of paper that summarised my childhood. I read countless police reports that I was a part of because of my mum, but they would refer to me as 'the subject':



I am not a subject or an object. Care Experienced people are not 'subjects' or 'objects', we are human beings with feelings that are valid, although it seemed relevant for professionals at this time to ignore that I had a name, never mind feelings.

A lot of my file was heavily redacted too, which means that due to the Data Protection act, any information that was regarded as third party would be blackened out, like this:



a12 (06/06)

#### 2 RESTRICTED

There are hundreds of pages that look like this. I understand that this was to protect my mother and her right to confidentiality, but these are chunks of my life that are missing and that I'll never be able to get back.

Reading my care records was really difficult, but I am happy that I got to find out things about my younger self that I didn't know before. I got to read the forms that I had filled in before going to children's panels when I was 7 years old and find out the things I liked doing, and it only reiterated how my love for writing, playing and listening to music has been apparent for so long, even in early childhood. When I was younger, all I wanted was to make a living from and study music at university; which I am now doing. I remember so clearly wanting to hold myself in that moment. I wanted to give my tiny self a huge hug and tell her she would be okay. I knew that she would be - I was so, so proud of her.

My experience of accessing my care records is my story, and each individual has another just as important. We can help shape the future of the processes around our care records, but we cannot do it alone. Care Experienced people want you to treat our care records with respect and honesty. I am considered lucky to have been able to access my care records, as many Care Experienced people aren't able to for a multitude of reasons, some as simple as moving to a new city and not having their local authority take consideration of it. It is a really important and life-changing step for all of us, and it is something that should be given the utmost attention and respect from all of the service providers and organisations involved in the process. This could be our only chance at understanding who we were throughout the adversity that we faced during our childhoods, or the only chance to remember parts of our life that we did not know about.

### **RECOMMENDATIONS**

These recommendations detail changes the campaign group want to see across the Subject Access Request (SAR) systems across all 32 local authorities in Scotland, which Care Experienced people rely on to access their care records and other personal information recorded whilst they were in care. They also set out how the impact of records on Care Experienced people's lives must be acknowledged by support being provided and also the ambition to 'future-proof' records as they are created.

#### **ACCESSING RECORDS**

## 1. Establish specific and appropriate processes for access to care records

We recognise that local authorities deal with a variety of information requests through the Subject Access Request process. Therefore, there must be a separate policy created on how to respond to SARs which are for and about Care Experienced people. Care records will exist for all those who have been 'looked after' and so uniquely affects the Care Experienced population. This must be recognised as distinct from other routine SAR processes.

#### 2. Create a friendly, person-centred approach to communication

We know that the communication from local authorities around Subject Access Requests can be impersonal, distant and difficult to understand. We want to see a transparent process, without suspicion and which recognises the duty of the local authority to provide Care Experienced people with their information. Also, there should be honest feedback & transparency if records are difficult to reach, lost due to fire, flood etc.

### 3. Ensure a transparent and honest approach to timescales

The Information Commissioners Office states that the local authority must respond up to one calendar month after a SAR has been made, however this can be extended up to two months if there are complications. We understand there are real practical difficulties in compiling and sorting personal information for Care Experienced people, however, there is currently a lack of communication from local authorities on why there are delays and the likelihood of meeting set deadlines. We need to see more open and equal dialogue between SAR teams and those accessing their records, to building understanding.

### 4. Create a rational and proportionate approach to redaction

The current practice around redaction of information, is extremely varied and often overused to a concerning level, as well as being inconsistent between local authorities. It is important that care records are viewed with a specific focus around the impact of redaction in affecting the ability of those accessing their records to make sense of their lives and understand a timeline of events leading to and during their care journeys. There are valid reasons why information sometimes cannot be disclosed, however, there must be more open dialogue between SAR teams and those accessing their records about why information is redacted and what else they can do to support any gaps in knowledge to be filled.

## 5. Simplify the SAR process so that individuals can access all their records in one application.

All organisations involved in an individual's care journey, i.e. police, health, education should be included as one subject access request. Sometimes this can help fill in blanks from a social work report or vice versa, to create a fuller narrative of life events and perspectives of professionals involved in a person's care journey.

#### **IMPACT OF RECORDS**

# 6. Provide meaningful emotional and psychological support for people accessing records

The emotional and psychological support provided for Care Experienced people accessing records is limited and as with other parts of the SAR process, is inconsistent across different local authorities. There must be optional tailored support available for those with Care Experience to access, if required. This support should be in line with trauma-informed and skilled best practice. Those within the SAR team must be able to communicate this support to Care Experienced people, to ensure they can access any resources available.

#### WHAT IS CAPTURED IN RECORDS

## 7. Develop a compassionate future-proofed approach to compiling records

A recognition of the importance of records for Care Experienced people means developing a 'future-proofing' approach to compiling records for those in care now and those coming into the system in future. Records should present, as far as is possible, a coherent narrative and should include personal/family photographs, school report cards, certificates and records of achievement and other appropriate objects and documents. We want to influence current practice of how records are created and make sure this is a nationally-endorsed approach. All records should be put together for Care Experienced people at the end of care, to make later access easier and a more simplified process. Also, when leaving care there should be the option to request files to take with them.

## 8. Establish a national working group of Care Experienced people and practitioners to keep developing practice

A regular forum is required to check ongoing change and follow-up commitments from local authorities to make improvements in their SAR processes. This group should also work alongside current practitioners to ensure those in care have a high-standard of care records which are created to a high quality. This group should proactively monitor and inform the implementation of any national guidance and be able to support the continued development and improvement of records access processes for Care Experienced people. This group could also feature best practice and help connect local authorities with each other's progress.

#### **DAVID'S STORY**



When a few of my friends told me that they had received their care records, I asked how they had done this and they told me that I should just google it, from this I found out that I could submit either a subject access request, or I could call, so I chose to call.

When I called, a member of staff had a brief discussion with me in order to ascertain my care details, previous addresses, previous names etc and explained that due to previous name changes, the process may take longer than others. After taking note of my details, the staff member explained me through the process of redaction, confidentiality and asked how I would prefer to receive

my records, to which I stated I would prefer a physical copy through the mail.

At the time one of my internal worries was that of price, however without asking the staff member managed to place my reservations at ease by explaining that there was no need for a service charge.

Upon receipt of my records, even though I had taken considerable time to decide I wanted to access them, I found myself to be extremely overwhelmed, upon reflection I was almost paralysed with anxiety about what might be inside the envelope.

It took me almost a week from receiving them before I could open them, and even then, I struggled to look at them, this was due to a mix between nostalgic emotion, overwhelming anger (due to unresolved issues) and an unchallengeable sense of dread, all from a small pile of paper.

This process in its entirety has taken me almost three years and I am only now managing to look at the pages as a pile of paper and not a direct representation of my life, which I know it is, but before now I would envision the paper as parts of me that had been written and designed by strangers that happened to run routinely segmented portions of my day.

I feel that though I struggled with this process, the application process was very helpful and pleasant, thereafter however is where I started to struggle, I don't remember ever being offered any support in processing the records, where as colleague and friends of mine have been offered in other local authorities. In which I would argue that we require a full, thorough, service user friendly and mirroring process across all local authorities with respect to accessing care records.

## CHANGE IN ACTION: ABERDEEN SPOTLIGHT

Aberdeen City Council has been working hard on developing a best practice approach to records and how these are accessed and kept and written about Care Experienced people in Aberdeen. ACE (Aberdeen Care Experienced) is the community of Care Experienced young people working to influence young person-led change in Aberdeen. The group works to ensure that the voice of Care Experienced young people is included and embedded into everything related to them in Aberdeen.

ACE were invited into this process from the very beginning and have taken an active role ever since. This includes sharing lead roles on two of the three working groups, and space being made for the active inclusion of the lived experience and voices of Care Experienced people.

A significant part of this work entails the development of ongoing training for social workers on writing records. ACE approached the council about developing videos of Care Experienced people talking about what it is like to be written about by others, and the will be embedded into the training. This will be an extremely powerful way to ensure that everyone understands what it is like to have an identity created for you, and how the effects of this can be felt throughout your life. To date, five young people are participating in this project.

Aberdeen Council is actively demonstrating the importance of genuine participation of young people and while this is often challenging, this project shows that it is not impossible.

#### LYNDA'S STORY



I only recently applied for my Care Records, on 31st January 2019.

I haven't received them yet even though it's been more than 30 days. At first, I didn't know if I had done it right. I spent a lot of time second-guessing myself, wondering if I had added enough information.

Two weeks after I first applied, I sent another email to ask if they had received it. I eventually got an email apologising for the delay saying that they had received it and it was being processed. I was expecting the records on the 1st March- a Friday. I decided to put aside the whole weekend to read them

and try to make sense of them. It was really stressful, and I felt very uneasy in the lead up to March 1st, not sure of what I might find out and how I would cope with all the information. Now the 30 days are over, I am still waiting but I now don't even have a date to focus on.

I left care 26 years ago, so I don't remember very much. I think I've blanked so much of it out. I didn't know I could get the records until 5 years ago when I started studying social care at college. I also didn't really fully understand that I am Care Experienced until last year when I got involved with Who Cares? Scotland.

I want to see my records as I'm on a sort of self-discovery journey. I've just gone through life with blinkers on. I've never been in that place to be able to look at all the things that happened to me. But now I am. I think I need to find out about my childhood more so I can understand myself more.

I also recently found a diary from when I was 15. I don't remember writing it or the events in it, but I talk about a social worker, and panel coming up. I think this is another sign that I should access my records.

I don't know what's going to come back-there's a reason why I've blocked it all out.

I'm nervous that I might find out things about my sisters because they were older than I was and weren't taken away. I am going to make sure my friend is there when I read it. It's going to be difficult, but I think I need to know.

### **OUR PROCESS**

#### Session 1: Our Lives, Our Stories, Our Records

6<sup>th</sup> November 2018

The first session involved looking at what records mean and how to access them. Care Experienced members of the campaign also shared detailed accounts of personal experiences of accessing their records and why, in some cases, they had not accessed them. The workshop also focused on:

- Discussion around narrative and self-esteem: Eamonn McCrory's research on memory.
- Who was able to support the campaign: CELCIS, Information Commissioner's Office,
   Gaynor Clarke Aberdeen City Council
- Legislation and policy overview of data rights.
- An input from Gaynor Clarke on practice perspectives, sharing experience from working within a decision-making role on records in a local authority.
- The possibility of developing a national practice model looking at process of access, the content of records and the support potentially needed.

#### **External Event: Aberdeen City Council**

7<sup>th</sup> December 2018

The event in Aberdeen was organised by the local authority and the group were invited to speak together for the first time about the campaign publicly.

- Three alumni members travelled to Aberdeen to give an input to practitioners from Aberdeen City Council, at an event raising awareness of the issues involved in accessing records for those with Care Experience.
- A personal account of accessing records was shared, presenting the real challenges and potential negative impacts of a local authority not getting this right.
- The aims of the campaign group were also presented, based on the first workshop's discussions and professionals interested in supporting the project were identified.

#### Session 2: Our Lives, Our Stories, Our Records

29th January 2019

- Discussed next steps for the campaign about how to increase visibility and involve more local authorities, to build on the Aberdeen event.

- Explored further the subject of care identity and how records relate to the shaping and defining of that identity.
- Reviewed the recommendations created so far for changing records access.
- Started creating case studies and an input for an event in March with local authorities.

#### Session 3: Our Lives, Our Stories, Our Records

26<sup>th</sup> February 2019

- Reviewed the edited report and finished recommendations.
- Finalised case studies to show personal stories of records access.
- Prepared presentation for event with local authorities on 7<sup>th</sup> March.

#### LEE'S STORY



Throughout my life I always seemed to have difficulty with belonging, settling down and building positive community links and relationships. For me to break the repeat cycle of homelessness, depression and toxic connections I moved to an area where I was unknown and had no support. Having taken this step, I started the journey of self-healing and trying to understand myself better, I soon realised there were too many unanswered questions and too much missing for me to gain a full picture of how I ended up where I was. I had questions such as "Why did I receive so little support?" "Why wasn't I ever informed or asked about the things

going on in my life?" "What happened back then?" All I can remember is how I felt and small snippets of what took place, there was just too many gaps for me to process. Although I told myself that it wasn't my fault, I had so many questions as to what went wrong and why I felt lost.

I had no idea how to apply for my care records or even the language to use to request them. I went to where I knew and asked them for information. They told me to apply online and that I had to pay a fee, they also informed me of the time it can take for these requests to come through. The form online was difficult to fill in completely as there was only some dates I can remember, so I know I do not have all the information held on me. I gave the only information I could remember which was details of an incident. I did get the papers within the time frame they stated however I was asked to make an appointment to go through my papers. I didn't request this or was really informed of why I had to do this, so I did worry about the reasons behind it. I asked my brother to come with me to support and read them with me, this was a tense situation for us both because we both deal with our childhood very differently. Walking into the room we were greeted with a setting that looked like a board room, three social workers, one of which was involved with our case then. This put both me and my brother on edge immediately.

This social worker then proceeded to tell us how lovely it was to see us doing so well and had our case come across there desk nowadays, we would all have been taken out of the house immediately. My brother's response to this statement was "What  $F^{*****}$ g use is that to us

now?" This meeting had not started well. The papers were considerably thin and had a lot of redaction. There were large chunks of redaction, however, it was inconsistent as there were some names blacked out and others not. They gave away enough detail for me to find out who had made the initial complaint although they wanted to remain anonymous etc. They redacted a huge part of what I had said and what was said about me. The information given to me only left me having more questions and having no where to be able to get them, as I was being told this was it.

Some of the information within the papers really felt like a kick in the gut and at one point my brother abruptly got up having to leave the room. The social worker tried to follow him and my brother (not so kindly) told him to step off him and give him space. This shifted the atmosphere in the room and I felt like I just needed out. I felt like I couldn't process what I was reading, I could not react how I wanted to because some of the stuff I was reading was making me really angry, especially after the social workers comment. I could not relax in that forced setting, I wasn't given the option of any other ways of dealing with it either.

During the reading of my care records I noted that there were decisions made about me and my brothers that we had no knowledge of, such as being put on the "At risk" register. We had known and accepted that we were let down back then, however, when reading recorded statements such as: "They arrived in the office hungry and dirty" Or "Lee has told us the perpetrator has moved back into the residence" Or "We WITNESSED the perpetrator being violent and abusive", I was less sure about my knowledge of what had happened. I remember being told things at the time such as "I am sorry, we do believe you but we cant help you", or there was too much red tape and their hands were tied so they couldn't protect us.

After reading my papers, I felt more hurt by these phrases because they stated clearly that we were in desperate need of protection. I felt like even the process of reading my papers was done in a way to suit others and not about my need for respect and dignity and choice as to how I would like to deal with it all. It left me feeling like I needed more information due to the little information that was provided and the fact that I knew there were more agencies who were involved in my care journey. Having approached another organisation and being told that my request for information was denied - after having to wait the full given time and pay a fee - I feel the whole process didn't answer anything for me, and has left it as another part of my life that's just shit.

My care journey consists of kinship Care, foster Care, looked after at home, homelessness then throughcare, before a decade of homelessness. It's a large amount of time to have no answers for. After reading my papers I realised that my "care" journey was longer than I had first thought, raising questions about my identity. Where was the real me or was I only a product of my circumstance? Was any of what I had done up until that point been me or was it all survival? Having the understanding that care today and legislation today is different from when I was in care, means I am not looking to be able to place blame, I just want to fill in the blanks. I want to make sense of the worst time in my life, however, I cannot do this with the little information I remember. If I could go back in time, I feel like I would try to access this information sooner. I had to wait till I was brave enough to make the switch from survival and completely reinvent myself in a different local authority to have that courage. I was never informed of my rights or about the decisions that were being made about my life and I wanted to unearth the processes that took me down the path my life took.

If I could change the process in accessing my care records it would be that it would involve one form that gives you access to all records and from all organisations involved during the time of your care journey and I would have redaction reduced to a minimum of names only. When reading and accessing records the offer of support should certainly be there, but how that support should look is up to the individual. Give them that choice. Make it a relaxing atmosphere not a board room that can easily trigger, the papers are difficult to read, so providing an environment that is stressful is counter productive to offering "support."

## Our Call to Action – Join Us!

This report is just the start of what our group want to achieve, please keep engaged in our work by following the #OurCareRecords hashtag on social media.

We are looking to make connections across Scotland to keep growing this work and to help share good practice, as well as keep involving Care Experienced people in the changes which take place.

If you would like to get in touch with those working on this issue, please contact: <a href="mailto:lhughes@whocaresscotland.org">lhughes@whocaresscotland.org</a>

Thank you!