

INFORMATION SHEET

Frequently Asked Questions 2

Answered by the legal panel - Last updated: 30th July 2020

About the legal panel

Several years ago, CBF Trustees identified the need to make better use of the legal framework for enabling families to get the right support for their relatives.

An initial meeting was held including CBF, Mencap, Irwin Mitchell and Leigh Day and it was agreed that we would set up a “legal panel”, with a protocol to gain initial advice at an early stage. The legal panel is now made up of a number of law firms and barristers specialising in learning disability, enabling a co-ordinated approach to emerging issues. The panel is well placed to identify strategic issues and cases that will have the greatest impact, and is part of a wider approach to getting the right level of legal support for families at the right time (e.g. utilising template letters and other resources as appropriate to ensure early resolution to legal issues).

Over the past couple of weeks, legal panel members have been considering questions families have raised with us related to the coronavirus pandemic. The second set of answers they have put together are below.

To read the first set of questions answered by legal panel members, please see the Covid-19 Information and Resources page on our website [here](#).

With very grateful thanks to the lawyers, barristers, and others who have generously provided their time and expertise to produce this FAQ resource.

TOPICS COVERED BY QUESTIONS

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*We know this is a very challenging time for families caring for loved ones with severe learning disabilities. These FAQs may raise further queries or you may have further questions that you would like answered – if so please let us know and we will do our best to address them. With the legal panel members we will be working on additional resources to address the issues raised so far. To share queries or further questions, please email info@theclub.org.uk and include **LEGAL QUESTION** in the subject.*



HOME SCHOOLING A CHILD WITH AN EHCP

Q: MY CHILD HAS AN EHCP AND ATTENDS A SPECIAL SCHOOL. HE IS CURRENTLY BEING EDUCATED AT HOME, HOWEVER THE SCHOOL ARE INSISTING I COMPLETE A TWICE DAILY REGISTER SO THEY CAN CHECK HE IS SAFE, OTHERWISE THEY WILL INSTIGATE SAFEGUARDING / ATTENDANCE PROCEEDINGS. THIS IS DISPROPORTIONATE AND INEFFECTIVE AND DO I HAVE TO COMPLETE THE REGISTER?

A: The Department of Education's guidance "Coronavirus (COVID-19): safeguarding in schools, colleges and other providers" – last updated on 27 March 2020 - states that:

Local authorities and schools do not need to complete their usual day-to-day attendance processes to follow up on non-attendance. Schools/colleges and social workers should be agreeing with families whether children in need should be attending education provision – and the school or college should then follow up on any child that they were expecting to attend, who does not. Schools and colleges should also follow up with any parent or carer who has arranged care for their children and the children subsequently do not attend. To support the above, schools and colleges should take the opportunity when communicating with parents and carers to confirm emergency contact numbers are correct and ask for any additional emergency contact numbers where they are available. In all circumstances where a vulnerable child does not take up their place at school or college, or discontinues, the school or college should notify their social worker.

However, the guidance above relating to "following up" only relates to children where care or education has been arranged away from the home and they do not attend. There are no equivalent provisions for 'follow up' for children where it is agreed they will be educated at home.

In addition, the "Coronavirus (COVID-19): guidance for schools about temporarily closing" - updated

9 April 2020 - states that:

- *During this period, schools do not need to take an attendance register. For administrative purposes Code # (planned whole or partial closure) should be used.*
- *Parents will not be penalised if their child does not attend school.*

Accordingly, provided it has been agreed between the School and parent that the child should not attending School or any alternative setting that has been arranged; there appears to be no legal basis for a School to require completion of a register in this way.



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Where such policies are being imposed by a School, the parent may want to raise this with their local authority, local MP or the Department of Education.

In relation to the threatened penalties if the register is not completed:

- Assuming there are no other safeguarding concerns, it is difficult to see how it would be lawful for a School to make a safeguarding referral to a local authority for this reason alone. Should a referral be made in these circumstances, legal advice should be sought.
- A School has no power to 'instigate' attendance proceedings. A School is only able to make a referral to a local authority. It is then for the local authority to decide whether any further steps should be taken. The local authority would not be able to impose any penalties for non-attendance because it has been agreed by the School. Any parent who is facing prosecution for non-attendance in these circumstances should take legal advice.



VISITING RIGHTS FOR FAMILIES

Q: I AM KEEPING IN CONTACT WITH MY SON WITH LEARNING DISABILITIES WHO LIVES IN THEIR OWN HOME SUPPORTED BY STAFF, BY VISITING WEEKLY STANDING IN THE GARDEN MAINTAINING THE TWO-METRE SEPARATION. HOWEVER, I AM CONCERNED THAT THE POLICE WILL QUESTION THIS AS I AM OVER 70 AND CLASSED AS HIGHER RISK. DOES THE NEEDS OF THE RELATIVE, WHO NEEDS REASSURANCE TRUMP THE AGE-RELATED RESTRICTIONS?

A: The government's "[COVID-19 guidance for residential care, supported living and home care](#)" was withdrawn on 13th May 2020. The Department of Health and social care are developing replacement supported living guidance. However in the absence of any guidance families are being faced with a number of issues for people in supported living. The CBF have raised their concerns around the delay in issuing guidance and Rook Irwin Sweeney have written a pre-action letter before claim to Secretary of State for Health and Social Care, Matt Hancock, urging the Government to produce guidance in relation to supported living. To see Rook Irwin Sweeney's press release and redacted copy of the letter sent to Matt Hancock, please see here: <https://rookirwinsweeney.co.uk/challenge-to-lack-of-covid-19-guidance-for-people-in-supported-living/>

Q: CAN PROVIDERS RESTRICT OLDER CARERS VISITING THEIR RELATIVES BECAUSE OF THE CARER BEING OVER 70 AND THEREFORE A HIGHER RISK GROUP?

A: The new [NHS visitor Guidance](#) states that the restrictions on visiting have now been lifted and is up to the discretion of local NHS trusts and bodies. It does stipulate that bedside visitors will be limited to one person. However, those who are there to support the needs of a patient, such as a familiar carer/supporter/personal assistant, should not be counted as an additional visitor. Patients may also be accompanied where appropriate and necessary to assist with the patient's communication and/or to meet the patient's health or social care needs. Where possible patients should contact the ward or department in advance to discuss local considerations and make appropriate arrangements.

The guidance does not include any additional restrictions where carers or relatives are in a higher risk group. If you are restricted from visiting your relative solely because of your age, or because you fall in the "vulnerable" or "extremely clinically vulnerable" group, you should explain to the provider that neither the Government's guidance nor the Regulations impose additional restrictions on your movement, and that it is your choice whether to accept the additional risk. If you are prevented from



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visiting your relative solely on this basis, contact the CBF who can refer you to specialist solicitors.

Q: I AM OVER 70 AND LOOK AFTER MY SON WITH LEARNING DISABILITIES AT HOME. HE NEEDS SUPPORT WITH EVERYDAY TASKS. I AM WORRIED IF I BECOME ILL WITH THE CORONAVIRUS I WILL NOT BE ABLE TO CARE FOR HIM, AND WORSE IF I GO INTO HOSPITAL WHAT WILL HAPPEN TO HIM, SHOULD THE LA BE PUTTING IN PLACE PLANS IN CASE I AM ILL?

A: Unless and until local authorities trigger the “easements” to their Care Act duties, they are under a duty to meet the social care needs of individuals in their area. If you become unable to provide care to your son, either because you are unwell or because you are in hospital, the local authority has a statutory duty to identify alternative care and support. Even if your local authority implements the Care Act “easements”, it is very likely that it will be required to provide care and support to prevent a breach of your son’s rights under the European Convention. It is strongly advised to contact the local authority to request that they prepare a contingency plan with you at this stage. If the local authority fails to identify a contingency plan, contact the CBF who can refer you to specialist solicitors.

Q: MY SON LIVES IN SUPPORTED LIVING, AND WE SEE HIM REGULARLY EVERY WEEK. ROUTINES ARE IMPORTANT TO HIM. WE ARE A CRITICAL PART OF HIS SUPPORT TEAM AND NEED TO CONTINUE TO VISIT AS USUAL. WE ARE HAPPY TO ADHERE TO STRINGENT HYGIENE. CAN WE BE CONSIDERED AS PART OF “HIS TEAM” AND OFFERED TESTING SO THAT WE CAN DO THIS SAFELY?

A: The government’s “[COVID-19 guidance for residential care, supported living and home care](#)” was withdrawn on 13th May 2020 The Department of Health and social care are developing replacement supported living guidance. However in the absence of any guidance families are being faced with a number of issues for people in supported living. The CBF have raised their concerns around the delay in issuing guidance and Rook Irwin Sweeney have written a pre-action letter before claim to Secretary of State for Health and Social Care, Matt Hancock, urging the Government to produce guidance in relation to supported living. To see Rook Irwin Sweeney’s press release and redacted copy of the letter sent to Matt Hancock, please see here: <https://rookirwinsweeney.co.uk/challenge-to-lack-of-covid-19-guidance-for-people-in-supported-living/>



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Q: I KNOW OF AN OLDER CARER WITHOUT ACCESS TO THE INTERNET WHO HAS NOT BEEN MADE AWARE OF THE GOVERNMENT GUIDELINES AROUND CORONAVIRUS. WHAT CAN I DO?

A: There is no general requirement for the Government and NHS to ensure that the guidance reaches everybody in the country. However, all public bodies will need to consider their duty under the Equality Act 2010 to make reasonable adjustments for disabled people, and this may include making coronavirus guidance accessible to all. It is arguable also that the government has a positive duty under Article 2 of the ECHR to take proactive steps to preserve life, which may mean an assertive communications plan to those difficult to reach.

The Government's coronavirus guidance has been primarily published online, as well as broadcast on television and radio, and in some instances sent by post. There will be some people in the country who do not have access to the internet and for whom up-to-date guidance will be more difficult to access (over 90% of households in the UK are thought not have internet access of some kind). Where these individuals are carers, it is likely that meeting the individual's needs for care and support will require ensuring that the carer is aware of the Government and NHS guidance, for instance the guidance on social distancing.

Q: NOW THAT LOCKDOWN RESTRICTIONS ARE EASING, HOW CAN WE BE ASSURED THAT CARE HOMES FOR PEOPLE WITH LEARNING DISABILITIES WITH NO UNDERLYING HEALTH PROBLEMS WILL NOT BE TREATED THE SAME AS CARE HOMES FOR VULNERABLE PEOPLE WHO MAY BE ISOLATED FOR LONGER WITH RESTRICTIONS ON VISITING FOR A LONG PERIOD? WE NEED TO BE ABLE TO VISIT OUR RELATIVES AS SOON AS POSSIBLE AND NOT BE IMPOSED TO ANY ADDITIONAL UNNECESSARY RESTRICTIONS WHEN LOCKDOWN IS EASED

A: When a care home decides to restrict visitors, this decision interferes with their residents' right to enjoy their private and family life. Public bodies (which can include care homes, even if their fees are paid for privately by residents or their families) are not allowed to interfere with that right, which is protected by Article 8 of the European Convention on Human Rights ('ECHR') - unless they have a lawful reason for doing so. There is also a prohibition on 'blanket bans', which means that public bodies are not allowed to apply policies to everyone indiscriminately irrespective of an individual's specific circumstances. We are aware that these restrictive practices are being used during the lockdown: please take a look at [these FAQs](#) from the Challenging Behaviour Foundation. Elsewhere in this guide we listed some alternatives that care homes can use instead of restricting visits.



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Once the UK government has ended the lockdown, it will be even harder for care homes to keep these restrictive measures in place without proper evidence that, for example, they have done so only after consulting medical experts who have confirmed that their residents remains at a particularly high risk of becoming infected. Even in those circumstances, we would expect the care home to take all possible measures to avoid a breach of Article 8 such as providing PPE to visitors or facilitating visits in a wing or building that is separate from the rest of the care home and can be disinfected quickly and thoroughly between visits.

If, after the lockdown, you or your relatives find yourselves in a situation where you are still being prevented from visiting a loved one in a care home then you should ask the care home manager why that decision has been taken. If you believe the decision may be unreasonable, or if you do not receive a response, then you should contact a solicitor promptly for advice about a potential judicial review challenge against the care home's blanket ban.

Judicial review is the process by which a High Court judge sitting in the Administrative Court considers the lawfulness of a public body's action, inaction, guidance or decision. This type of challenge is governed by Civil Procedure Rule 54 which prescribes the time limit for filing such a challenge as "promptly, and in any event not later than 3 months after the grounds to make the claim first arose" [CPR 54.5(1)]. The first step of a judicial review challenge is to send a legal letter in accordance with the Pre-Action Protocol for Judicial Review (known as a 'pre-action letter'), putting the care home on notice that their blanket restriction may amount to an unlawful interference with your family's Article 8 rights. Many judicial review challenges settle at the pre-action stage because a letter from a solicitor's firm is often enough to force the decision maker to review and revoke an unlawful policy, or to obtain a detailed Letter of Reply which provides evidence and proper reasoning for the implementation of a policy.

Q: I AM WORRIED MY SON'S CARE HOME WILL NOT ALLOW HIM TO LEAVE TO ATTEND A CLOSE FAMILY MEMBER'S FUNERAL AND THEN RETURN AGAIN. I BELIEVE THIS WOULD BREACH HIS HUMAN RIGHTS BUT HAVE BEEN TOLD THAT IN SOME CIRCUMSTANCES THESE BREACHES WOULD BE ALLOWED. IS THIS RIGHT?

A: Taking steps to prevent someone from being able to attend funeral (either through not letting them go, or saying they cannot return if they do) would be an interference with a person's right to a private and family life under Article 8 European Convention on Human Rights. However, Article 8 is a 'qualified' right, which means that a public body can interfere with your rights where it is lawful, necessary and proportionate in order to protect:

- national security



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- public safety
- the economy
- health or morals
- prevent disorder or crime, or
- the rights and freedoms of other people.

Action is 'proportionate' when it is appropriate and no more than necessary to address the problem concerned. It isn't possible to provide general advice on when a particular interference might be considered necessary and proportionate as every case will turn on its individual facts. Where there is a concern that human rights are being breached, advice should be sought.

Q: I'M CONCERNED THAT MY RELATIVE'S CARE PROVIDER WILL PREVENT ME FROM CONTACTING HIM/HER VIRTUALLY DUE TO CONFIDENTIALITY ISSUES. WHAT SHOULD I DO?

A: During the Covid-19 lockdown, many residential/care homes are using a variety of technology, such as FaceTime, Skype and WhatsApp, to allow residents and their families to stay in touch.

Using this technology raises a number of legitimate security and confidentiality concerns (for the resident, other residents as well as staff) and so it is vital that care homes perform a proper risk assessment and then have procedures in place to ensure that the use of this technology is compliant with the GDPR. However, the fact that so many care homes have taken steps to enable these virtual visits would suggest that, with suitable safeguards, these issues are far from insurmountable.

The British Geriatrics Society has recently recommended that *"Care homes should take advantage of videoconferencing software on smartphones, tablets and portable computers as much as possible to maintain human contact for residents. They, and healthcare professionals supporting them, must recognise and respond to the strain that social isolation puts on residents and their families."*

<https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes>

Therefore, if a particular care home is seeking to argue that they are unable to arrange virtual visits as it would breach ill-defined "data protection" requirements then they should be requested, in an email or letter to the home's Data Protection Officer (they are required to have one), to set out these concerns in more detail and why they cannot be satisfactorily addressed, particularly as they appear to have been addressed elsewhere. If you remain unhappy with the response, then you



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should then complain to the Information Commissioner's Office (ICO) and / or the Care Quality Commission (CQC) or seek legal advice.

It is likely that a different approach may be taken in relation to different methods of virtual communication and those with 'drop in' capability for example, may require a tailored agreement in terms of using that facility covering for example security measures to prevent unwanted requests, scheduled times for use of 'drop in', management of notifications etc.

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RIGHT TO APPROPRIATE MANAGEMENT OF BEHAVIOURS THAT CHALLENGE

Q: I AM WORRIED THAT THERE IS NO APPROPRIATE MANAGEMENT IN PLACE IN CASE MY RELATIVE'S BEHAVIOURS CHANGE.

A: There is no reason why your loved one should not continue to receive appropriate care and behaviour management during the pandemic. The NHS has also provided [guidance](#) on the specific needs of those with autism and learning disabilities. You can read this guidance here, and the Government has also advised those working in the social care sector to take account of it. Importantly, the NHS guidance refers to the need to listen to families and carers and to make reasonable adjustments.

The Social Care Institute for Excellence (SCIE) has recently provided guidance for families, care staff as well as social workers/OTs on supporting people with learning disabilities and autism through the pandemic and you can find this [here](#). SCIE stresses the need to promote the human rights of those with learning disabilities and autism. Even if your local authority has decided to operate the Care Act [easements](#), it is still required to take a person- centred approach.

If you are concerned about the way in which your loved one's behaviour is being managed you should raise your concerns with the provider and commissioner of their care. You may wish to draw some of the guidance above to their attention. If you are not able to agree a way forward, please contact the CBF and ask for a referral to the legal panel.



GOING INTO HOSPITAL DURING COVID 19

Q: MY SON WAS ADMITTED TO HOSPITAL, AND I NOTICED THAT “NOT FOR ESCALATION” WAS WRITTEN IN HIS NOTES- WHAT CAN I DO?

A: The first thing you should do is speak to the healthcare professionals treating your son and ask for clarification of what you have seen, and for an opportunity to discuss it.

“Not for escalation” is a term often used to mean that a patient will receive palliative or ward-based care only, and will not be escalated to the High Dependency Unit or Intensive Care Unit even if their health declines.

Any decision about a patient’s care and treatment should be based on their individual needs and wishes, however it is lawful for healthcare professionals to consider what resources are available when considering what treatment they can offer to their patients.

You should speak to the healthcare professionals to confirm what decision has been made and on what basis. Any decisions based on blanket policies, such as the age of your son or that he has a particular disability may be unlawful and if that is why your son has been designated “not for escalation”, you should consider seeking formal legal advice.

If the decision has been made due to your son’s specific circumstances, then although you should have been consulted so that your son’s wishes could be taken into account, if the medical experts consider that more invasive/a higher level of treatment would be futile in that it would not likely to lead to him recovering, this is very difficult to challenge. You should ask for a fresh decision to be made if you were not previously consulted and listen carefully to the reasons given if the only option being offered is “not for escalation”.

If you disagree with the clinical judgment of the healthcare professionals you can ask for a second opinion and this should be provided. Again you and your son if appropriate/possible, should have the opportunity to provide your views. A second opinion may be from a doctor in the same hospital but should be someone not previously involved. If they too reach the view that your son would not benefit from a higher level of care and/or that it is in his best interests not to receive more invasive painful treatment when prospects of recovery are very low, then although there may be an option of seeking further opinions, any legal challenge to the decision is unlikely to succeed.

If there is a dispute about what is in a person’s best interests who does not have the mental capacity to make it themselves, proceedings can be brought in the Court of Protection and specialist legal advice is recommended. It is worth remembering however that the Court will not compel any doctor to take action which they consider



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may harm their patient and so having a supportive medical expert is usually crucial to succeed. Often having had further discussions and consultations with the treating team an agreement can be reached which may for example include having a timescale for review or a more specific approach to further interventions.



EMPLOYMENT ISSUES

Q: CAN YOU PROVIDE MORE CLARITY AROUND THE 80 PERCENT OF PAY WHEN THE USUAL PAY IS SO VARIED DUE TO THE HOURLY PAY?

A: How much pay an employee is entitled to depends on what the employer has agreed with them to pay, or what the employer has varied their entitlement to, if you have a variation clause in your employment contract. Please remember the Scheme does not change employment law, so existing contractual rights remain.

The Scheme sets a minimum of the lower of 80% of their regular wage or £2,500.

On 17 April 2020 HMRC issued Guidance to help calculate pay for employees whose pay varies: <https://www.gov.uk/guidance/work-out-80-of-your-employees-wages-to-claim-through-the-coronavirus-job-retention-scheme>

For employees whose pay varies and who were employed from 6 April 2019, the Government advice is that the employer can claim the highest of either:

- 80% of the same month's wages from the previous year (up to a maximum of £2,500 a month)
- 80% of the average monthly wages for the 2019 to 2020 tax year (up to a maximum of £2,500 a month)

To calculate 80% of the same month's wages from the previous year:

- Start with the amount earned in the same period last year.
- Divide by the total number of days in this pay period including non-working days.
- Multiply by the number of furlough days in this pay period.
- Multiply by 80%.

Employees whose pay varies and who started employment after 6 April 2019, the Government advice is to claim for 80% of their average monthly wages since they started work until the date they are furloughed, up to a maximum of £2500 per month.

To work out 80% of an employee's average monthly earnings:

- Start with the amount they earned in the tax year up to the day before they were furloughed.
- Divide it by the number of days they've been employed since the start of the tax year – including non-working days (up to the day before they were furloughed or 5 April 2020 – whichever is earlier).
- Multiply by the number of furlough days in this pay period.
- Multiply by 80%.



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Every day or period after the employee commenced employment with the employer is counted in making this calculation. This includes days when no work was undertaken.

For employees who have been employed for less than a month, their earnings so far should be pro-rated.

Some employers may take the view that those casual or zero hours workers and employees who are not guaranteed work from the employer do not need to be put on furlough leave at all because the employer can instead simply refrain from offering them work. However, this approach is not in the spirit of the scheme which intends to ensure that employees and PAYE workers retain a basic income during the crisis stages of the pandemic and if you are in this situation, you should seek further legal advice.

Q: WHAT IS THE SITUATION IF AN EMPLOYEE REQUESTS THAT RATHER THAN RECEIVE SSP THEY WANT TO RECEIVE 80% OF THEIR USUAL SALARY AS THAT IS THE HIGHER AMOUNT? WE (THE PROVIDER) ARE CLEAR THAT THE 80% IS ONLY AVAILABLE FOR THOSE INDIVIDUALS WHO HAVE LOST THEIR JOBS AS A RESULT OF THE CORONAVIRUS SITUATION BUT UNDERSTANDABLY, 80% IS A MUCH MORE ATTRACTIVE OFFER TO THE SSP AMOUNT OF £94.25 PER WEEK.

A: The precise application of the Job Retention Scheme is untested and Government Guidance is constantly evolving. To afford yourselves some protection, we advise those making decisions in relation to furlough, to record the date you make your decision and that you review it regularly. The Government are fine tuning the policy and issuing regular updates – the last one in respect of SSP the 19 April 2020.

For an employee **in receipt of SSP** the answer is 'no' they cannot be furloughed. The Revised Guidance states that *'you cannot claim for employees while they are getting SSP, but they can be furloughed and claimed for once they are no longer receiving SSP'*

The eligibility criterion appears to be 'receipt of SSP' and not absence by reason of ill-health, which suggests to us, that an employee who is on long term sickness absence, but who has exhausted their SSP entitlement, might be entitled to furlough pay. The Government has been asked to clarify this issue.

The recent Government update has confirmed that employees who are furloughed and who then become unwell are not entitled to SSP. This is important clarification and we assume has been given to ensure that employers do not fall foul of the 3 week minimum furlough period.



CARE ACT EASEMENTS

Q: I HAVE HEARD THAT MY COUNCIL DOES NOT NEED TO MEET THE NEEDS OF DISABLED ADULTS DURING THIS PANDEMIC, IS THAT RIGHT?

A: It is correct that the Coronavirus Act 2020 downgrades a wide range of Adult Social Care duties under the Care Act 2014 by introducing what it calls ‘easements’. Most significantly it could include converting the duty to meet someone’s needs into a power to do so, unless failing to meet those needs would result in a breach of a person’s human rights.

However the guidance published by the Department of Health and Social Care states that any local authority should only be operating under the ‘easements’ as a matter of last resort, and prescribes a very detailed process before any decision can be taken, which in effect mean that the ‘easements’ should have least impact possible and for the shortest period of time possible.

The guidance states:

A Local Authority should only take a decision to begin exercising the Care Act easements when the workforce is significantly depleted, or demand on social care increased, to an extent that it is no longer reasonably practicable for it to comply with its Care Act duties (as they stand prior to amendment by the Coronavirus Act) and where to continue to try to do so is likely to result in urgent or acute needs not being met, potentially risking life. Any change resulting from such a decision should be proportionate to the circumstances in a particular Local Authority.

This means that your local authority would have to be able to show that the ‘workforce is significantly depleted, or demand on social care increased, to an extent that it is no longer reasonably practicable for it to comply with its Care Act duties’ and also that ‘to continue to try to do so is likely to result in urgent or acute needs not being met, potentially risking life.’ We would therefore very much expect this to be the exception, rather than the norm.

Local Authorities have to keep a record of the decision, with evidence that was taken into account. Where possible the record should include the following:

- The nature of the changes to demand or the workforce
- The steps that have been taken to mitigate against the need for this to happen
- The expected impact of the measures taken



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- How the changes will help to avoid breaches of people’s human rights at a population level
- The individuals involved in the decision-making process
- The points at which this decision will be reviewed again

Importantly, this decision “should be communicated to all providers, service users and carers. The accessibility of communication to service users and carers should be considered...” and that “The provision of information and advice for public reassurance will be particularly important during this period.”

If anyone has had their care cut as a result of these easements, we would advise them to seek immediate legal advice.



INFORMATION SHARING

Q: FAMILIES ARE FREQUENTLY SHARING THAT THEY ARE TOLD THAT THEY DO NOT HAVE A RIGHT TO SEE INFORMATION KEPT ABOUT THEIR RELATIVE UNDER THE GUISE OF CONFIDENTIALITY. WHAT IS THE LAW AROUND INFORMATION SHARING WITH FAMILY CARERS, WHOSE RELATIVE LACKS CAPACITY IN RELATION TO PERSONAL INFORMATION KEPT ABOUT THEM BY THE LA OR CCG?

A: Professionals such as healthcare or social care workers have a legal obligation of confidentiality to individuals they are treating. They must also comply with data protection law, which requires, among other things, that personal data is used fairly and only for specified purposes.¹ Third parties such as family carers generally do not have a right to see information about someone they care for. The person to whom information relates must consent to sharing information. You can ask for this consent at any time and it is best for consent to be expressed in writing. If a person does not express consent professionals may only share information in limited circumstances, for example following a court order or to prevent serious crime.

In the event that an individual lacks capacity to consent to share information professionals may still be able to release information to carers. However, this will depend on whether carers formally represent the individual, for example as a deputy; on what information is being sought; and whether a disclosure is in the individual's best interests.² The Mental Capacity Act s 1(2) sets up a presumption of capacity; unless there is a specific finding to the contrary, individuals may still consent to information sharing, even if they lack capacity to make other decisions. Professionals must be satisfied it is in the best interests of an individual who lacks capacity to share health and social care information with a third party.³ If you do receive confidential information about a person who lacks capacity, you must also keep it confidential and only use it for the purposes it was shared for.

What is the law around sharing of information with organisations such as the CBF in relation to safeguarding or when acting in a family advocacy capacity on behalf of family carers and liaising with health and/or social care. How can we challenge decisions not to share information that it would be in the best interests of an individual to share.

If an individual consents to their personal information being shared with an advocacy organisation, or one of the other limited reasons for disclosure applies, then it must

¹ General Data Protection Regulation (2016), Article 5(1).

² Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (2007), para 16.8.

³ *Code of Practice* (n 2), para 16.19.



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be disclosed. In this respect the law applies to organisations such as the CBF and to family carers in the same way. Because third parties do not have rights for the purposes of confidentiality or under data protection law, the options for challenging refusals to share information are limited.

An avenue that is open to third party carers and advocates alike is to follow an organisation's complaints procedures. If information is withheld by an NHS or local authority social care organisation it may also be worth contacting the organisation's Caldicott Guardian. This is intended to be a senior person whose role is to give advice and to ensure that patient information is used according to legal and ethical standards and they are meant to be the '*conscience of the organisation*' in matters of confidentiality and information sharing.⁴ They work on the basis of the Caldicott principles, including the seventh principle that: '*the duty to share information can be as important as the duty to protect patient confidentiality*'.⁵

Where an individual lacks capacity, decisions about whether information sharing is in their best interests can be challenged in the Court of Protection. Specialist legal advice should be sought if it appears that a decision needs to be challenged in this way. If the case is urgent, it may be necessary to ask the court for a decision without going through complaints procedures beforehand.⁶

⁴ UK Caldicott Guardian Council, *A Manual for Caldicott Guardians* (2017), p 3.

⁵ *Manual* (n 4), p 5.

⁶ *Code of Practice* (n 2), para 16.32.