

Anne's Law: proposals for adults living in care homes to maintain family and friendship connections

November 2021

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Introduction

In September 2020 the Scottish Human Rights Commission (the Commission) <u>raised concerns</u> with the Clinical and Professional Advisory Group for Care Homes in Scotland, regarding the arrangements for visiting residents in Scotland's care homes during the pandemic. This followed the issue being raised with us during <u>our impact monitoring work</u> on social care, as well as a number of people contacting us directly to raise concerns.

The Commission stressed that the human rights of residents and their families, as well as staff, should be central to decisions on visiting, and set out the main human rights considerations that applied to arrangements for visits in the context of a virus that threatens the right to life. We recommended that explicit reference to human rights ought to be made in the guidance on visiting, and that care home managers should be supported to make human rights based decisions in individual cases. We also recommended that those with direct experience, including residents and their families, should be involved in the development of guidance.

The <u>evidence</u> submitted by Care Home Relatives Scotland in relation to Petition PE1841/B, to which this consultation relates, indicates that the guidance on visiting may not have been implemented consistently, with the possibility of visiting varying across the country and from care home to care home. Residents and their families were left with the view that they were being denied contact with one another without justification. From this it appears that the guidance on visiting did not achieve the desired outcome of supporting meaningful contact with those in care homes safely, while protecting the rights of others.

However, what is not clear from the terms of the consultation is why the guidance was apparently not implemented consistently. In order to ensure that the correct remedial action is taken, it is first essential to understand what caused the issue. Therefore, while we welcome the Scottish Government's commitment to addressing this important issue, we reiterate our recommendation that a human rights based approach be applied in doing so, both in assessing why these issues arose in

relation to visiting and in identifying appropriate remedial steps to ensure a better outcome going forward.

Human Rights Based Approach

In taking a <u>Human Rights Based Approach</u> (HRBA), the Commission recommends employing the PANEL principles (Participation, Accountability, Non-discrimination and equality, Empowerment and Legality). Applied to these proposals, the following aspects become evident:

Participation	Everyone has the right to participate in decisions which affect them. Participation must be active, free, and meaningful and give attention to issues of accessibility, including access to information in a form and a language which can be understood.
Accountability	Accountability requires effective monitoring of human rights standards. For accountability to be effective there must be appropriate laws, policies, administrative procedures and mechanisms of redress in order to secure human rights.
Non- discrimination and equality	A human rights based approach means that all forms of discrimination must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most vulnerable situations who face the biggest barriers to realising their rights
Empowerment	People should understand their rights, and be fully supported to participate in the development of policy and practices which affect their lives. People should be able to claim their rights where necessary.

Legality

The defining characteristic of a HRBA is that it engages with human rights standards and works to embed them in all structures and processes from the outset. This means engaging with the requirements of the human rights framework and applying it consistently, evidently and intentionally to each proposal.

A human rights based approach ought to be adopted in determining what steps should be taken to effectively remedy the issue that has been identified, as we discuss further below. However, the principles can also be very usefully applied in determining why the existing guidance did not achieve the desired outcome:

Participation: was there participation of those who would be most affected by the guidance?

Accountability: was there a way for residents and their families to hold decision makers to account for failure to apply the guidance in a manner that upheld human rights?

Equality: was there consideration of the need to eliminate discrimination and prioritise the most vulnerable?

Empowerment: were residents and families empowered with knowledge and understanding of their rights and the ways in which they could assert their rights?

Legality: did the guidance explicitly reference applicable human rights standards and were care homes supported to make human rights based decisions about visiting?

Reviewing what went wrong with the implementation of the guidance, with reference to the above PANEL principles, will be essential in order to ensure that measures taken to address the failings are appropriate and adequate. The apparent lack of such analysis makes it difficult to comment on how Ministers can ensure the current proposals are effective in addressing the problem.

Recommendation 1: We recommend that the Scottish Government apply a human rights based approach to determining:

- 1 why the guidance on visiting care home residents did not achieve the desired outcome of supporting meaningful contact with those in care homes safely, while protecting the rights of others.
- 2 what steps should be taken to effectively remedy the issue.

With that substantial caveat, in the following submission we set out: the main human rights engaged by this issue; the circumstances in which some of the relevant rights may be lawfully restricted, and, to the extent possible at this stage, the application of PANEL principles to the general proposal. In the course of doing so we address the specific questions raised in the consultation in so far as possible:

- Do you agree with the overall aim that people living in adult care homes have the right to see and spend time with those who are important to them in order to support their health and wellbeing?
- What do you think should be the main aims of Anne's Law?
- Do you think this should be a right for residents or for the visitor (s)?
- How can the rights of residents be balanced against the rights of other people in the setting for example other residents, staff, visiting professionals?
- What do you see as the main benefits, challenges and risks of the proposal to develop legislation to support people living in adult care homes to have the right to see and spend time with those who are important to them?
- Should the proposals apply only to people who live in an adult care home (residential and nursing) registered with the Care Inspectorate?

The Human Rights Framework

The right to life

Throughout the pandemic the Commission has emphasised the positive obligation on the state to take appropriate steps to protect life. The right to life is protected under Article 2 of the European Convention on Human Rights (ECHR). Fulfilment of this right requires the taking of preventive measures in certain circumstances. This right applies to everyone, including care home residents, their families, and staff.

The European Court of Human Rights (ECtHR) has held that Article 2 imposes an obligation on the state to do "all that could have been required of it to prevent the applicant's life being avoidably put at risk". The obligation applies when the state knew or ought to have known of a threat to life and has been found to apply in a number of different settings, including the unintentional loss of life resulting from dangerous activities.

The ECtHR has stated the obligation "must be construed as applying in the context of any activity, whether public or private, in which the right to life may be at stake". The obligation to "take appropriate steps" to protect life is relevant in the health and social care field and is discussed further in our earlier briefing on care homes.

The Article 2 right to life is non-derogable, which means that the state cannot depart from its obligations even in times of war or other national emergency and, since it is an absolute duty, the justifications available for interference in qualified rights such as Article 8 do not apply.

In addition, the right to health is provided for in the International Covenant on Economic, Social and Cultural Rights, which has been ratified by the UK and so is binding on the UK, and in turn the Scottish Government¹. The right to health is significant in this context as a duty owed to residents, visitors and care home staff which, in a pandemic, may require the application of infection control measures.

The right to private and family life

The Commission agrees that people living in adult care homes have the right to see and spend time with those who are important to them in order to support their health and wellbeing. This is an aspect of the right to respect for private and family life, home and correspondence in Article 8 EHRC.

"Private life" encompasses a person's physical and psychological integrity.²

"Family life" is particularly relevant to care home visiting, since an essential element of family life is developing and sustaining relationships with family³ and enjoying each other's company⁴. For example, during the initial phase of lockdown, the English Court of Protection was asked to rule on family contact and residence in the context of a terminally-ill care home resident seeking to live with family and held that the right to die with one's loved ones was covered by Article 8⁵.

While care homes may have some institutional characteristics, they will often be the residents' "homes", with the attendant Article 8 rights, as well as the practical and emotional implications this brings.

The right to meaningful contact with family, including for those residing in care homes and for their families, is therefore already covered by the ECHR, which is incorporated into Scots law through the Human Rights Act and the Scotland Act.

In certain situations these rights may need to be balanced against the rights of others, such as the right to life and the right to health, as referred to above. The way in which that balancing is undertaken is through careful application of the test for lawful restrictions of qualified rights.

Justification for interference

Article 8 is a qualified right, which means interferences are permitted only if they are: in accordance with the law; in pursuit of a legitimate aim; and necessary in a democratic society. Generally, interferences will be

considered necessary in a democratic society for a legitimate aim if they answer a "pressing social need" (such as public health reasons), if they are proportionate to the legitimate aim pursued and if the reasons given by national authorities to justify the interference are relevant and sufficient.

In determining whether a measure is 'necessary in a democratic society', the case-law of the ECtHR reflects the need to balance an individual's interests protected by Article 8 against either the general public interest, or the interests of third parties as protected by other provisions of the Convention and its Protocols.

This balancing exercise is one of the ways by which the human rights framework can assist in resolving situations of competing rights and interests, such as when public health concerns conflict with individuals' right to family life.

The test of 'proportionality' can be further broken down by considering the following questions:

- (1) whether the objective of the measure is sufficiently important to justify the limitation of a protected right,
- (2) whether the measure is rationally connected to the objective,
- (3) whether a less intrusive measure could have been used without unacceptably compromising the achievement of the objective, and
- (4) whether, balancing the severity of the measure's effects on the rights of the persons to whom it applies against the importance of the objective, to the extent that the measure will contribute to its achievement, the former outweighs the latter

In essence, the question at step four is whether the impact of the rights infringement is disproportionate to the likely benefit of the impugned measure.⁶

These tests can be applied to measures which restrict visits to care homes. The objective of protecting life by controlling the spread of a

deadly virus is both sufficiently important to justify limitation of Article 8 rights (Step 1) and rationally connected to that objective (Step 2).

A measure that was once accepted as proportionate may subsequently cease to be so, having regard to changing circumstances. This underpins the principal that interferences in protected rights should always be time-limited.

Step 4 points to the need for individualised risk assessments. Such risk assessment must take into account the risks to the person's emotional wellbeing and mental health of not having visits.

Article 8 also imposes a positive obligation upon the State to secure respect for the right to private and family life where the restrictions on that right are being placed not by State agents but by private actors such as care providers.

The right to liberty and security of person

Article 5 ECHR protects against arbitrary or unjustified deprivations of liberty. Deprivations of liberty may take numerous forms, and determining whether someone is deprived of their liberty within the meaning of Article 5 requires an assessment of facts on a case by case basis. The degree of social contact available to a person is one factor, taken within the wider context, that will be relevant. The Commission notes that other restrictions have been experienced by care home residents, for example reduced social contact in communal areas of care homes and restrictions on movement within the care home itself. The overall impact of restrictions on social contact would have to be taken into account in assessing whether a particular situation amounts to a deprivation of liberty.

It is also well established that in a deprivation of liberty situation, visiting arrangements also engage Article 8 rights. 7

Article 5 is a limited right, which means that deprivation of liberty will only be permissible where it is in compliance with substantive and procedural domestic law⁸ and falls within one of the 15 permissible grounds for deprivation, this list being exhaustive and to be interpreted narrowly.

Where these tests are met, a number of procedural safeguards apply, such as the right to bring a legal challenge to the lawfulness of the detention and the right to compensation where detention is found to be unlawful. 11

The Commission has previously indicated that some people in Scotland's care homes may have been placed in circumstances that amount to a deprivation of liberty under Article 5 ECHR, for example people being moved from hospitals to alternative care settings. The Commission has highlighted the importance of procedural safeguards, particularly when people are moved from hospitals to alternative care settings, such as care homes.

The above analysis is not intended to be exhaustive, and other rights including the right to non-discrimination on grounds such as age and disability (Article 14 ECHR and reflected across UN human rights treaties including the CRPD), and the right to autonomy and participation in decision-making (Article 8 ECHR and Article 12 CRPD) are also relevant.

The human rights framework described above provides a clear set of agreed standards to assess impacts and decisions against. Where careful balancing of rights is required in decision-making, human rights provides a legal basis for doing so. Any new legislation will similarly need to provide a means to balance these competing rights, and in a way that is compliant with these existing human rights.

Recommendation 2:

We recommend that:

1 - in assessing the potential benefits of introducing a specific legislative right, consideration is given to the rights that already apply to care home visiting, and

2 - in considering the potential risks of introducing a legislative right, consideration is given to any potential for confusion, uncertainty and/or inconsistency between existing rights and new legislative rights.

Analysis of proposal

Below we have considered the main benefits, challenges and risks of the proposal, as well as the question of scope, applying the PANEL principles, making recommendations where appropriate.

Participation

While we welcome the opportunity to comment on these proposals, there are inherent limits to the participative value of a standard consultative process such as this. The British Institute of Human Rights has voiced concerns about the human rights implications of typical government approaches to policy consultations, citing inaccessible documents, short response periods, and 'consultation fatigue' as examples of some of the factors which undermine their effectiveness¹².

In this context, we note that this consultation was only open from 24 September – 2 November, a period of just 5 weeks.

We note that the process includes some targeted engagement with those most effected in the form of two workshops specifically for care home and supported housing residents. However, we also note that the latest available figures¹³ suggest there are over 4000 care settings potentially affected by the proposals.

The Commission is therefore concerned that the steps taken to date are not sufficient to secure the level of participation required.

Recommendation 3

In developing this proposal further, Ministers should undertake a much broader consultation or participation exercise to hear directly from

those most affected by the new measures and ensure their views are reflected in the decisions being taken.

Accountability

As is explicitly recognised in both the PANEL principles and the human rights legal framework, all rights must have a corresponding effective remedy. The Commission has previously highlighted long-standing and systemic problems with access to justice for those who believe their human rights have been breached. We note that the proposal does not cover enforcement or redress.

The Scottish Government has overall responsibility for respecting, protecting and fulfilling human rights, those contained in the ECHR and other international human rights instruments ratified by the UK Government. The Human Rights Act incorporated the ECHR into UK law, as a consequence of which ECHR rights can be relied upon directly in our national courts.

In terms of Section 6 of the HRA, it is unlawful for a public authority to act in a way which is incompatible with a Convention right. In this context, 'public authority' includes private bodies when they are carrying out public functions.

While it seems clear that it was intended that Section 6 would cover all care home providers, court interpretation of Section 6 has complicated matters, leading to uncertainty. On one interpretation, only publicly-funded residents in care settings are able to raise claims in court based upon the Human Rights Act¹⁴. This would be an inconsistent and inequitable position, even although it may be possible to assert a claim against the Scottish Government for failure to protect the human rights concerned.

The Commission <u>has written</u> in more detail on this point and welcomed the Scottish Parliament's approval of clearer wording in the <u>UNCRC Bill</u>, which clarified that "'functions of a public nature' includes, in particular, functions carried out under a contract or other arrangement with a public authority.")

Recommendation 4:

We recommend that any specific legislative right covers all care home providers, public or private, in order to avoid any uncertainty as to the application of the right in the private sector.

Recommendation 5:

We recommend that consideration be given to available mechanisms for review of decisions regarding visiting residents in care homes, the adequacy and accessibility of such mechanisms and steps required to empower people to access a review of the decision.

Non-discrimination

Any provision which aims to support individuals' rights must be designed in such a way as to ensure broad and equitable entitlement to those rights. In particular, entitlement should not be withheld arbitrarily from particular groups or categories of individuals. To do so may mean that the provisions fall foul of Article 14 ECHR (Protection from Discrimination).

It is therefore important to consider who would be excluded from the new rights if they only applied to people who live in an adult care home (residential and nursing) registered with the Care Inspectorate.

We understand that, like hospitals, hospices are regulated by Healthcare Improvement Scotland and not the Care Inspectorate.

By definition, those residing in hospices will be nearing the end of life. As last year's litigation in the English Court of Protection showed¹⁵, Article 8 considerations assume particular importance in cases of terminal illness, where contact with family can profoundly impact the quality of life.

Empowerment

If residents and families felt unable to effectively challenge decisions taken by care homes around visiting arrangements then it is possible that a lack of awareness of existing rights under HRA, and existing mechanisms for review of decisions contributed to this.

Legality

As noted above, the visiting policies and decisions which may be affected by this proposal are already subject to a detailed framework, which includes clear standards and guidance, including the Human Rights Act 1998 and Equality Act 2010.

The application of the Human Rights Act is discussed above. The framework provided by the Equality Act 2010 also helps ensure decisions are made in a fair, transparent and accountable way, while considering the needs and rights of different groups. The application of this framework to residential care settings is explained in a briefing by the Equality and Human Rights Commission¹⁶.

There is a risk that fresh legislation will merely duplicate - or worse, conflict with - these existing provisions.

If the primary object of these proposals is to ensure that policies and decisions concerning care home visits respect the human rights of those involved, it is not clear how the introduction of a new legislative framework on top of that which already exists will support this.

We note that the <u>Principles to Open with Care</u> set out in last year's guidance listed 'Respect for human rights' as one of eight principles to be followed when considering approaches to visiting. The other seven principles were 'Responsibility'; 'Maintaining well-being'; 'Safely balancing risks of harm'; 'Equitable access for all residents'; 'Individualised approach'; 'Equality/ choice' and 'Flexibility'.

As set out above, the existing human rights framework expresses and reflects these principles. Significantly, it also provides a mechanism for balancing different rights and resolving conflicts arising both between the rights of different individuals and between individuals and the general interest in protection of life and infection control.

Nevertheless, the evidence from Care Home Relatives Scotland and others indicates that the existing rights framework failed in practice to adequately protect the rights of residents and their families over the past 18 months. As set out in our introduction, it is critical that the reasons for

that failure are identified in order to understand how best to support the full realisation of these existing rights.

Recommendation 6: We recommend that the proposals should be underpinned by clear analysis of the existing legal and regulatory framework so that any new legislation serves to harness its strengths and address its shortcomings.

Conclusion

We recognise that the current consultation seeks responses to a proposed principle, with the detail of how the principle is to be realised in legislation yet to be set out.

We anticipate that many respondents will share our position in broadly supporting the aim of the proposed legislation. However, without further detail, it is difficult to comment on whether the proposed legislation will achieve that aim. Similarly, the absence of detailed analysis of the problems the proposed legislation is intended to cure limits our ability to make strong fact-based recommendations.

Assuming this consultation reveals broad support for the principle, we would encourage Ministers to adopt a fully-participative human rights based approach to the assessment of why the aim was not realised in practice and the steps that ought to be taken to ensure full realisation of the relevant human rights going forward.

¹ Although the ECHR does not explicitly guarantee the right to health, the case-law European Court of Human Rights (ECtHR) has gone some way to incorporated it within the positive obligation to secure the right to life. Lopes de Sousa Fernandes v Portugal [2017] ECHR 1174 at paragraph 166

² Niemietz v Germany, no. 13710/88, 16 December 1992.

³ Marckx v. Belgium, § 31 ⁴ Olsson v. Sweden (no. 1), § 59

⁵ VE v (1) AO (By her litigation friend, the Official Solicitor), (2) The Royal Borough of Greenwich, (3) South East London CCG. [2020] EWCOP 23.

⁶ Bank Mellat [2013] UKSC 39 per Lord Reed at paragraph 74

⁸ International law may also be applicable; see *Medvedyev and others v France* [GC] 2010

⁷ Khoroshenko v. Russia [GC], 2015, § 110. It has also been held that it is an essential part of a prisoner's right to respect for family life that the prison authorities assist him or her in maintaining contact with his or her close family. Chaldayev v. Russia, § 59

⁹ ECHR Article 5(1)(a-f)

¹⁰ ECHR Article 5(4)

¹¹ ECHR Article 5(5)

¹² Government Policy (bihr.org.uk)

¹³ 2017 figures; statistics.gov.scot

¹⁴ See Care homes: Visiting restrictions during the covid-19 pandemic - House of Lords - House of

Commons (parliament.uk) at paragraph 11.

15 See VE v (1) AO (By her litigation friend, the Official Solicitor), (2) The Royal Borough of Greenwich, (3) South East London CCG. [2020] EWCOP 23 referred to above and also *BP. v Surrey County Council and RP*. [2020] EWCOP 17.

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