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Elberte v. Latvia: whose tissue is it anyway – relational autonomy or the autonomy of relations?

Authors: Edward S. Dove^{1*}, Agomoni Ganguli Mitra¹, Graeme T. Laurie¹, Catriona McMillan¹, and Samuel Taylor-Alexander¹

Affiliations:

¹JK Mason Institute for Medicine, Life Sciences and the Law, School of Law, University of Edinburgh, United Kingdom.

*Corresponding author: Edward S. Dove, University of Edinburgh School of Law, Old College, South Bridge, Edinburgh EH8 9YL, United Kingdom; E-mail: edward.dove@ed.ac.uk; Phone: +44 (0)7487 726657.

Abstract

A European Court of Human Rights decision rendered in January 2015 (*Elberte v. Latvia*) has raised a curious question regarding the nature and scope of the right for relatives to consent to or to oppose the removal of a deceased person's tissues. The decision suggests that Council of Europe member states must clearly define the scope of the right for relatives to express their preferences for removal of a deceased's tissue or organs – provided such a right has been created in law – and member states must define the corresponding obligation or margin of discretion conferred on experts or other authorities to explain these rights to the relatives. Notwithstanding, this article asks whether the decision could open the door to a free-standing *right* for relatives to oppose removal of their deceased relative's tissues or organs, regardless of the deceased person's own wishes, in the name of the relatives' human 'right to respect for private life'.

Keywords

Consent, donation, human rights, organ and tissue removal, private life

Introduction

Few subjects in life seem to raise as much consternation and circumspection as death. Not only do many of us fret over how and when we will die, and what will become of our patrimony and loved ones, we also have concerns – and try to attend to those concerns – over what will come of our bodies. Many wish to exercise choice during life over bodily remains in death. Such choice draws in familial and social considerations. When it comes to possible removal and donation of tissues, organs or whole bodies, choice is exercised often through communication with loved ones and some contemplation of prevailing social norms. Some choose to ‘dedicate’ their bodies or parts thereof to others, perhaps altruistically in the hope of furthering medical research or the lives of strangers or connected others, whereas others choose to be disposed of ‘whole’ – body and spirit as one – without any removal of the flesh.

Allowing freedom of choice over what happens to one’s own inchoate cadaver has become a much-debated topic.¹ A driving question for policymakers has been whether donation of tissues, organs or bodies should be the default position of the citizenry, with the available choice reduced to ‘opt out’ (i.e. refuse otherwise presumed donation), or whether each citizen, with or without communication with loved ones, must ‘opt in’ to express affirmatively their willingness to donate. Coupled with this question is the role of both health professionals and relatives in determining the scope of consent to removal and donation. Who must communicate to whom, about what, and how? Unsurprisingly, local values and knowledge have led to varying legislative responses across the world. Some jurisdictions foreclose, at least in law, the relevance of the deceased’s relatives’ opinions on donation altogether, whilst others explicitly or implicitly incorporate and value them. One question has remained unanswered, however, in a court of law: What happens when a jurisdiction’s legislation acknowledges the relevance of relatives’ views on removal and donation, but does

not spell out the nature and scope of the rights, nor the corresponding duties of the parties in ascertaining and operationalising those views?

The member states of the Council of Europe have now been provided an answer, albeit a perplexing one. In a judgement rendered on 13 January 2015 (*Elberte v. Latvia*),² which followed a similar judgement rendered 6 months earlier,³ the European Court of Human Rights ('ECtHR') ruled that member states must define the scope of the right for relatives to express their preferences for removal of a deceased's tissue or organs – provided such a right has been created in law – and member states must define the corresponding obligation or margin of discretion conferred on experts or other authorities to explain these rights to the relatives. But in answering one question, the ECtHR's reasoning has critically raised another: Whether there could be a free-standing right for relatives to oppose removal of their deceased relative's tissues or organs, regardless of the deceased person's own wishes, in the name of the relatives' human 'right to respect for private life'. As such, the decision, which on a surface level is about the right of an individual to be free from arbitrary state intervention, upon further analysis raises deeper, anthropological, ethical and legal questions about the nature of autonomy in consenting to tissue and organ donation, for it indicates less a judicial acceptance of 'relational autonomy',⁴ and more a potentially worrying precedent of an 'autonomy of relations' between relatives. In this article, we engage in multidisciplinary analysis to query whether such a free-standing right could be invoked, and to explore the question: Just whose tissue is it, anyway? The implications may be profound for tissue and organ donation, specifically, and medical law and human rights, generally.

The Case

Factual background

On 19 May 2001, Mr Egils Elberts, a Latvian national, died in an automobile accident. The following day, his body was transported to the Forensic Centre in Riga, where

an autopsy was carried out. The Latvian Government alleged that after the autopsy, the forensic medical expert verified, as required by the law at that time, that there was no stamp in Mr Elberts' passport denoting his objecting to the removal of his body tissue. Nor were any objections to the removal by Mr Elberts' relatives communicated to the examiner. Consequently, a small portion of his body tissue was removed, purportedly, the Latvian Government claimed, for transplantation purposes. On 25 May, a relative retrieved the body and the next day, the funeral took place in Mr Elberts' home town. This was the first time Mr Elberts' wife, Ms Dzintira Elberte, saw her husband. She noticed that his legs had been tied together; he was buried this way.

Two years later, in March 2003, Ms Elberte became aware that tissue had been removed from her husband's body when the Latvian Security Police informed her that a criminal inquiry had been opened into the potentially illegal removal of organs and tissue from 1994 to 2003 for supply to a pharmaceutical company based in Germany. (Ultimately it was established that between 1999 and 2002, tissue had been removed from 495 people; in exchange for the supply of tissue, the German pharmaceutical company provided the Forensic Centre the financial means to purchase medical equipment and computers for medical institutions in Latvia.) Ms Elberte was recognized as an injured party in October 2003. However, between 2005 and 2008, the prosecutors and superior prosecuting authorities vacillated as to whether a criminal case could be brought against the forensic medical examiners.

In 2008, a group of forensic experts lodged an appeal contesting the reasons for their status as the persons against whom the criminal inquiry was instigated. On 26 June 2008, the Riga City Vidzeme District Court upheld their appeal. The court found that the relevant domestic law (Law on the Protection of the Body of Deceased Human Beings and the Use of Human Tissues and Organs in Medicine) ('the Law') as it existed from 1994 to March 2003

and tissues of a deceased person may not be removed against his or her wishes as expressed during his or her lifetime', [but] '*in the absence of express wishes*, removal may be carried out if none of the closest relatives (children, parents, siblings or spouse) objects.'⁵ On 27 June 2008, a final decision to discontinue the criminal inquiry was adopted due to Latvia's 5-year statutory limitation period for a criminal inquiry.

The ruling of the European Court of Human Rights

Ms Elberte lodged a complaint with the ECtHR on 5 December 2008 against the Republic of Latvia for violating three Articles in the European Convention on Human Rights ('the Convention'). Two are worth discussing in this article, one briefly and the other substantively.⁶

First, Ms Elberte alleged a violation of Article 3,⁷ as her husband had been buried with his legs tied together and his tissue had been unlawfully removed, which she alleged was inhuman or degrading treatment and left her with significant emotional suffering. This claim was ultimately successful, as the ECtHR found that Ms Elberte faced undue delay (she had lodged 13 complaints and 4 decisions had been quashed), uncertainty and distress concerning the nature, manner and purpose of her husband's tissue removal and that the anguish caused by seeing her husband's legs tied together when his body had been returned to her caused suffering that went beyond the suffering inflicted by grief following the death of a close family member. That the claim was successful is unsurprising. Although the ECtHR admitted that it had never previously questioned in its case law the profound psychological impact of a serious human rights violation on the victim's family member,⁸ it ruled that the facts of the case fell within the scope of the existing Convention jurisprudence that favours relatives who claim significant emotional suffering over how deceased loved ones are treated, especially where a key factual element is closeness of the familial bond and the way the authorities responded to the relative's enquiries.⁹

Second, and of more interest for present purposes, however, is the nature of Ms Elberte's other claim, namely, that her Article 8 right to respect for private life had been violated because her husband's tissue had been removed without his or her prior consent (which, based on our reading of section 4 of the Law, we take to mean more accurately a 'right to object'), and that in the absence of such 'consent' (as the claim had been framed), her dignity, identity and integrity had been breached. Ms Elberte claimed that the removal of her husband's tissue was an interference with her private life under Article 8(1) and that the interference had not been in accordance with the law and had not pursued a legitimate aim under Article 8(2), including to 'save and/or improve the lives of others', which the Latvian Government saw as falling under the heading of 'protection of health' and the 'protection of the rights of others' in Article 8(2). According to Ms Elberte's claim, the forensic experts should have sought her consent before removing Mr Elberts' tissue. Article 8 of the Convention reads as follows:

Article 8 – Right to respect for private and family life

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

The ECtHR noted that whilst the Latvian Government denied that Ms Elberte's claim concerned the 'family life' component of Article 8,¹⁰ the Government did not contest that it fell within the ambit of 'private life'. This itself is an interesting concession, as we discuss further below. Reiterating that the ECtHR has found the concept of private life to be a 'broad term not susceptible to exhaustive definition'¹¹ by citing its recent jurisprudence,¹² the ECtHR made a point of highlighting, rather succinctly, that neither party disputed that Ms

Elberte's right, established under the Law, to object to the removal of her husband's tissue came within the scope of Article 8 insofar as private life is concerned. Indeed, the ECtHR saw 'no reason to hold otherwise'.¹³ The rationale for excluding Ms Elberte's claim under the Article 8 right to family life was not pursued any further in the decision.

Article 8 protects an individual against arbitrary interference by public authorities, and according to para 2, any interference with one's right to respect for private life must be 'in accordance with the law'. Referencing *S. and Marper v. the United Kingdom*,¹⁴ the ECtHR emphasized that this phrase means that an impugned measure must have some basis in domestic law (i.e. a legal basis component), 'which should be compatible with the rule of law' (i.e. a rule of law component), that is, the domestic law 'must be formulated with sufficient precision and must afford adequate legal protection against arbitrariness . . . [and] must indicate with sufficient clarity the scope of discretion conferred on the competent authorities and the manner of its exercise'.¹⁵ Thus, the question before the ECtHR was whether Ms Elberte was unlawfully prevented from exercising her right to object to the removal of her husband's tissue after his death due to the Latvian authorities' alleged failure to ensure the legal and practical conditions for the exercise of that right.

Upon analysis, the ECtHR noted that Ms Elberte was never informed that her husband's tissue would be removed unless she expressed any contrary wish; this was apparently a common practice at the time. The ECtHR also noted that it was disputed whether the forensic expert had in fact verified that there was no stamp in Mr Elberts' passport denoting his objecting to the use of his body tissue. Ms Elberte claimed the passport had been at their home at the time. Moreover, the ECtHR noted that the authorities responsible for enforcing the Law – the Security Police and supervising prosecutors – disagreed as to the Law's scope of obligations in 2001, and this indicated a lack of sufficient clarity. Pulling these findings together, the ECtHR found that 'it remains unclear how the system of consent,

as established in Latvian law at the material time, operated in practice in the circumstances in which the applicant found herself¹⁶. In the circumstances that arose, positive obligations were owed by state authorities: ‘[i]f the wishes of the deceased are not sufficiently clearly established, relatives should be contacted to obtain testimony prior to tissue removal’.¹⁷

Because the law failed to establish administrative or regulatory mechanisms and clearly define the scope of the corresponding obligation or margin of discretion conferred on experts or other authorities to ‘explain these rights [to refuse the removal of a deceased person’s organs and/or tissue] to the relatives’,¹⁸ Ms Elberte had been unable to foresee how to exercise her putative right to object to the removal of her husband’s tissue. Consequently, the ECtHR found that the Law lacked sufficient precision and did not afford adequate legal protection against arbitrariness, accordingly concluding that the interference with Ms Elberte’s right to respect for her private life was not ‘in accordance with the law’ within the meaning of Article 8(2). Thus, her claim was upheld and she was awarded a total of EUR 16,000 in respect of non-pecuniary damage.

Discussion

Networks of actors and performing autonomy

In certain religious or cultural contexts, a dead body may be viewed as ‘impure’ or ‘dangerous’, and body parts may be viewed as holding the essence of a self. The ‘essential self’ of a person can be reflected in the limbs, face, heart and so forth. The removal of such a vital part of the body would reflect less an autonomous decision made by the deceased whilst alive and in communication with his or her relatives, and more an affront to the society’s belief system and an ‘injury’ to the deceased body or its soul, ill preparing its passage to another world. Autonomy, as understood by the notion of self-determination, is balanced with the collective values reflected in the belief system.

In other religious or cultural contexts, such as those in Council of Europe member states, the body and body parts generally are not viewed in this manner. If they were, the tissue and organ transplantation system would likely reflect a very different kind of practice.¹⁹ Procuring and harvesting of human tissue is made acceptable in a country like Latvia by treating a competent adult person as an ‘autonomous being’ capable of exercising choice over removal of organs and tissue, which in turn are viewed as (mere) parts (if not ‘waste’) of a self-determining body. Consequently, what we see in these contexts is a diverse but stable network of actors, from recipients and families of the brain-dead to governance boards and tissue/organ brokers, performing tasks that purport to maintain the autonomy (and anonymity) of donors.²⁰

At the same time, social scientists have observed how tissue and organ transplantation and emergent ‘tissue economies’ have resulted in novel understandings of human individuality and relatedness. Noting, for example, that donors (and families) and recipients alike often experience donation as a ‘gift of life’ that produces an ongoing bond between them, these studies challenge us to consider how classic notions of (atomistic) autonomy are reworked with, or undone by, developments in organ transfer and tissue exchange.²¹ These studies also point to how an increased flow of human tissue and organs, often between countries of unequal economic development, relates to transnational economic and technological imbalances. An ensemble of medical, scientific and politico-economic forces are creating new frontiers of ‘biocapital’, altering the relationship between countries and their citizenry in the process.²² Viewed from this perspective, the ECtHR’s endorsement of Ms Elberte’s right to refuse her husband’s tissue removal as an aspect of her ‘right to respect for private life’ glosses over how the classic notion of the autonomous individual as a stable, fixed, atomistic and encapsulated self is increasingly challenged by the ability and demand to harvest human tissue in an era of transnational, biocapitalized medical science.

Latvia's failure to provide a robust mechanism for giving proper effect to the self-determining rights and wishes of its citizens resulted in a destabilization of the network that allows for human tissue and organs to circulate anonymously and independently from the body of deceased and living donors. The murkiness surrounding whether or not Mr Elberts gave consent whilst alive, and the corresponding question of the legality of harvesting tissue from his body, brought into stark relief the inability of local institutional arrangements to maintain the rights and interests of the deceased in the face of broader trends in global scientific research and medical care.²³ Questions of control over tissue and agency and of how one should be treated post-mortem speak to the need to continually redefine the rights and corresponding duties of relevant stakeholders. How can, and how should, bioethics and the law – two systems both traditionally grounded in the concept of respect for autonomous individuals – respond to technological and sociopolitical changes that are challenging, if not outmoding, such a concept of the atomistic individual, especially if and when laws also recognize the legal claims of relatives with respect to the remains of a deceased family member?

Consent to what? And whose tissue is it anyway?

Viewed from an ethical perspective, the decision raises equally difficult questions. The central function of consent is traditionally seen to uphold the moral principle of respecting an individual's autonomy, that is, one's freedom of rational self-governance and selfdetermination.²⁴ Whilst there is considerable disagreement about the nature, scope or strength of this individual-centred principle,²⁵ as seen, for example, in the alternative concepts of relational autonomy²⁶ and 'caring autonomy',²⁷ there is a general consensus that consent means allowing a competent person to be 'actively involved in shaping and directing' all aspects of her life.²⁸ In the context of health care and biomedicine, such consent is characterised by intentionality, understanding and freedom from controlling (or undue)

influence.²⁹ The standard ethical procedure is one where consent is sought explicitly *from the person whose rights and interests are concerned*, unless the person is deemed temporarily or permanently incompetent, in which case consent is sought from a proxy or surrogate who might be best placed to know the individual's wishes. In some contexts, however, 'presumed consent' may be the operating paradigm, such as in an emergency situation where it is impossible to secure consent from the patient or a proxy in time without jeopardizing the patient's life.

For organ and tissue procurement after death, it is not a universally accepted moral principle that competent adults must expressly consent to the removal of their own tissue or organs. Indeed, there is no standard operating consent paradigm for donation. Countries may operate under a system of opt in (explicit consent), with the use of a donor card, for example, or under a system of opt out (presumed consent), where individuals are considered to have given consent to posthumous procurement of organs and tissue for research or medical purposes unless otherwise stated. Countries tend to operate under a sub-classification of these two systems; these are categorized as 'hard' and 'soft' opt in/opt out systems, with 'soft' systems allowing for the opinions of relatives to be considered and 'hard' systems disregarding consideration of such opinions. Douglas and Cronin remark that 'there is evidence that, in general, opt-out systems have higher donation, and lower refusal, rates than express consent (opt-in) systems'.³⁰

There is quite a bit of diversity in the spectrum of opt in / opt-out donation systems.³¹ At one end of the spectrum, a hard opt out system (e.g. as exists in Austria) allows health professionals to remove tissue or organs from every adult who dies unless a person has registered to opt out; objections from relatives are disregarded. At the other end of the spectrum, a hard opt in system allows health professionals to remove tissue or organs only from adults who have expressly consented to such removal, regardless of the relatives'

objections. Soft systems operate in between. As noted above, they allow for the considerations of relatives to be taken into account – but here there are critical distinctions. In some soft opt out countries, such as Belgium, health professionals can remove tissue or organs from every adult who dies, unless a person has registered to opt out, or the relatives object to removal and the relatives take it upon themselves to communicate with the health professionals. In these countries, there is no positive obligation of health professionals to consult with relatives. In other soft opt out countries, such as Spain, however, health professionals can remove tissue or organs from every adult who dies, unless a person has registered to opt out, but it is standard for health professionals to actively consult with relatives to obtain their agreement at the time of the person's death. Finally, in soft opt in systems, such as in England or Scotland, health professionals can remove tissue or organs from adults who have expressly consented to (or 'authorized') such removal, but generally health professionals will inform relatives that the person has opted in and the health professionals may choose not to proceed with removal if certain relatives object.

Surveying these various tissue and organ donation systems, it is evident that several types necessitate or encourage health professionals to communicate with (close) relatives, reflecting a concern that the deceased's relatives should have an opportunity to input on the proper way to dispose of their relative's body, particularly if the wishes of the deceased are not recorded. In this sense, the autonomy of the deceased person is always 'relational': the choice expressed by the person when alive is produced, reproduced and ultimately given effect through a network of institutions, individuals (e.g. health professionals and family) and the practices that bind them together – from face-to-face interaction to the signing of forms, the preparation of advance statements and the reviewing of passports.

Yet soft opt out systems that incorporate the consent (and its necessary corollary refusal) of relatives, whether through law or practice, intrigue us. Might we be asking both

too little and too much of consent in such a system? As Roger Brownsword notes, undervaluing consent is a concern in an opt out system if a country has not made its case for requiring participation: ‘To presume consent on the basis of an omission (non opt-out) is a fiction; and to purport to justify such a scheme by reference to consent might be a fraud, consent being deployed to defend the indefensible’.³² In this situation, the notion of the consent of relatives is a nonsense: they cannot consent to that which is unconsentable. At the same time, overvaluing consent can also be a concern in an opt out system where a country has made a legitimate case for requiring participation (i.e. a full, substantive justification). Does this system then need a consent-based justification in order to defend its legitimacy? We would respond in the negative, for no court of law has ruled either hard or soft opt out systems as per se violating human rights. So then why go to the trouble at all of seeking the consent of relatives, regardless of whether the deceased person opted out? We suggest that, quite simply, it is because it is ‘a local courtesy rather than a moral requirement.’³³ Opt out countries operate on the premise that citizens have a duty to participate; the justification for the system relies substantively on a rights-focused account of the public interest, not procedurally ‘in the supposed consent signalled by those who do not take steps to opt-out’.³⁴ If a country is relying on a non-consent-based, public interest justification (such as for the protection of public health), it makes little difference from a moral standpoint to inquire about the views of the relative. It is a courtesy, not a condition. In both instances, whether as overvaluation or undervaluation, consent is a distraction, not an imperative.

In an opt in system, as exists in England,³⁵ the role of a relative’s consent differs. Here, the system tends to place a premium on the (individual) autonomy of persons, allowing them to make a determination as to what happens with their body after death. If they express a wish to donate their tissue or organs, then that wish is theoretically (read: in law) respected, regardless of the wishes of the relatives. The relatives do not have any legal right or lawful

veto over those wishes; as such, there is no role for the consent of relatives. The relatives may opine and object, but they cannot agree to waive a right, for they have no *prima facie* right recognized in law in this situation.

Yet we know that in practice this does not happen. Even if an opt in system is couched in consent, as in England, ‘it is, in practice, still strongly influenced by veto insofar as both the donor and the surviving relatives can frustrate the other’s wish to donate – the former by way of statute, the latter by custom’.³⁶ In the case of England (and Scotland), relatives have no legal right or lawful veto over a deceased’s wishes, but nor do health professionals have a legal duty to comply with a deceased’s wish to donate. There is, therefore, significant space for manoeuvring around the letter of the law. For example, the NHS Blood and Transplant (NHSBT) Transplant Activity Report for 2013–2014 notes that the consent/authorization rate was 89% when the deceased’s wishes were known at the time of potential donation, but 119 families overruled their loved one’s known wish to be a donor.³⁷ This means that relatives can wield tremendous extralegal authority over a deceased’s body. Similarly, if deceased persons express or record no wish during their lifetime, health professionals may, through customary practice, approach relatives to establish any known wishes of the deceased.³⁸ Again, we emphasize that this is *not* a question of consent, but rather a gathering of evidence to determine the known wishes of the deceased. Another situation arises, however, where deceased persons never recorded any wishes, and those wishes are unknown by relatives. Here, a relative is asked by a health professional to consent, or perhaps phrased better, to *assent* – that is, to agree to waive the deceased’s person right to bodily integrity – a right which does not extinguish upon death.

What we see then is that in both opt out and opt in organ and tissue donation systems, there is only one scenario where consent from a relative is *true* consent: where the deceased was obligated to expressly authorize (i.e. opt in to) the removal of organs or tissue from his or

her body, did not do so and did not express his or her wishes to a relative whilst alive, and health professionals deem the tissue or organs viable for removal. Here, and only here, does consent of a relative play a viable role.

Yet, even here, we would argue that the consent is an expression of the relative's relational autonomy in the sense that it arises from the familial relationship and merely signals a waiver of the right to the bodily integrity of the deceased. It is similar to other proxy consents in that we can assume that the relative is acting according to what the deceased would have wished herself or himself. Ms Elberte denied this view, however, instead claiming that another right was implicated in her consent, namely, *her* right to respect for *her* private life. But how can this be if consent is understood as permission to waive the benefit of a right in question – be it privacy, confidentiality, bodily integrity and so forth? What right was Ms Elberte seeking to waive if not Mr Elberts' right to bodily integrity? Nothing in her claim suggested she sought consent as a means to give effect to Mr Elberts' wishes and to express relational autonomy in the sense outlined above; everything suggested she wished to exercise her own right to self-determination, a kind of autonomy of relations claim hung on a right to private life hook.

What might this right entail in the context of exercising an executive decision over the body of another, framed not as a waiver of a right of another but as an expression of a (presumably) decisional private life right of one's own? Indeed, if it is not about waiving a right to bodily integrity, but rather is about decisional private life, would a relative have a right to veto an express consent given by the deceased individual whilst alive, and if so, what exactly is the moral foundation of this right? Would it still be about 'respect for private life'? And how can we say consent in this context if it is really a matter of vetoing any action performed on another's body? Consent cannot be the right term to use in this case. Section 4 of the Law never used this term in relation to the relatives, and a 'right to object' is not

necessarily synonymous with consent, which is often treated instead as some form of active, affirmative permission and agreement.³⁹ Surely in a context as fraught as this, where consent is so contestable, the ECtHR would have done better to speak of permission or refusal *simpliciter*.⁴⁰

That the ECtHR avoided these questions points to the difficulty in defining the nature and scope of autonomy (or should we say autonomies?) in posthumous tissue and organ procurement and its relation to consent. If such decisions are truly left to the remit of the legislature and courts, the Latvian Government, in this case, does seem to have been operating under a soft opt out consent system (at least to a substantial degree), where individuals are provided an opportunity to opt out during their lifetime (by stating this in their passport) and where the (closest) relatives also have some nebulous right to veto removal in the absence of expressed wishes of the deceased. In this case, the driving ethical concern is whether: (1) Latvia had upheld its moral obligation in ensuring that its citizens had been made aware of the legitimate public interest behind the opt out system so that consent or authorization could be considered meaningful and (2) the system allowed relatives to exercise meaningfully their statutory rights in objecting to the removal. In accepting the claim as one of consent, and by forgoing deeper ethical analysis of this autonomy of relations approach, the ECtHR's invocation of Article 8's 'right to respect for private life' certainly would fit within Article 8 judicial precedent that engages the application of the right to respect of autonomy.⁴¹ Yet, it is precisely this framing, skirting of issues and lack of deep ethical analysis that troubles us about this decision and about what may come.

The legal impact

The ECtHR's decision encourages legislators throughout the Council of Europe's member states to ensure that if their tissue and organ donation laws allow for relatives to consent to or to refuse removal of a deceased's organs or tissue (as is the case, in varying modalities, in Belgium, Sweden, Spain and Italy, for example), they must be sufficiently clear in prescribing the positive obligations of authorities or health professionals to: (1) consult with these relatives (however so defined) prior to tissue or organ removal, (2) explain their rights to them and provide them with material information to make a meaningful decision, and (3) obtain their consent or refusal, as the case may be. This is not the same as suggesting that member states *must* provide a right to consent or refuse to relatives. Rather, the ECtHR has confirmed that – irrespective of the position that a country takes on a role for relatives in the disposal of the tissue or organs of a deceased relative – the manner and means to give proper effect to any right that is created must be in place to comply with the Convention and avoid arbitrariness. The issue in *Elberte* appears to be that Latvia created the problem for itself by establishing in its domestic Law a right for relatives to refuse a deceased relative's organ and tissue removal, but then failed to provide them with effective means to exercise this right. More profoundly, though, we wonder whether the ECtHR's decision has laid the foundation for a future, free-standing *right* for relatives to oppose removal of their deceased relative's tissue or organs, regardless of the deceased's own wishes, in the name of the relatives' human 'right to respect for private life'.

Indeed, in addition to the socio-ethical questions raised above, multiple legal questions arise from *Elberte*. The ECtHR's decision reads as though the pendulum of communicative responsibility swings only far left and far right; but just how far should an obligation fall on authorities such as health professionals to approach relatives and explain to them their rights? Is there any room for the responsibility to fall on relatives to express their consent or refusal

to authorities, as is the case in Belgium? What level of specificity is needed in the law to avoid the risk of arbitrary action by authorities? Given the procedural nature of this decision, which authorities should approach the relatives? How far and for how long should efforts to make contact be made? What happens when relatives disagree? Additionally, physicians, surgeons and forensic experts may not be in the best position to approach and communicate with relatives about removal and rights to consent or refuse, not least because of potential conflict of interest concerns. Should the state provide for specially trained ‘trusted third party’ staff like psychologists, counsellors and communication experts?

Another issue troubles us. Whilst acknowledging that it is not the role of the ECtHR to decide upon the legitimacy of consent systems and impose legal harmonization through judicial fiat, we do question why the ECtHR went to some lengths to deny the need to consider whether a presumed consent versus ‘explicit consent’ system operated in Latvia in 2001.⁴² However, much they skirted this question (and ensuing analysis under Article 8(2)) and framed it as a normative issue – when the parties framed it as an issue of factual determination – it nonetheless coloured the decision in a number of ways.

First, the ECtHR acknowledged that the parties’ views differed in the exercise of the closest relatives’ right to object. Ms Elberte rested her Article 8 claim on the argument that in 2001, an opt in (explicit) consent system operated in Latvia, and the experts had a positive duty to ask the ‘closest relatives’ whether any of them would consent or object the removal.⁴³ The Latvian government counterargued that the absence of any expressed objection by any close relative was sufficient to proceed with tissue or organ removal, that is, Latvia was operating within the legitimate confines of an opt out (presumed consent) system.⁴⁴

Second, the ECtHR supplemented its decision about the arbitrariness of the Latvian Law by referencing a number of European and international instruments on the matter of

tissue removal after death, which in its view accord ‘particular importance to the principle that the relatives’ views must be established by means of reasonable enquiries’.⁴⁵ We question why the ECtHR felt the need to reference these wider international instruments at all. If the issue before them truly was a question of discretion for each member state (‘Whichever [consent] system a State chooses to put in place . . .’⁴⁶), why was the focus not solely on the terms of the Latvian Law as it existed in 2001? More troublingly, only two of the cited instruments date prior to 2001. Disagreement with reference to any international instruments aside, it is our opinion that documents dated post-2001 should have had no impact on assisting interpretation of whether the Law was sufficiently clear *at the time of* Mr Elberts’ tissue removal.

Yet, even for the two pre-2001 instruments cited, the picture is less than clear. The 1978 Council of Europe ‘Resolution on harmonisation of legislations of member states relating to removal, grafting and transplantation of human substances’ recommended that a ‘state *may* decide that the removal must not be affected if, after such reasonable inquiry as may be practicable has been made into the views of the family of the deceased, [. . .] an objection is apparent’.⁴⁷ No further guidance on the manner and means to give proper effect to this inquiry is provided. The other document, a 1998 Opinion from the European Group on Ethics in Science and New Technologies to the European Commission, entitled ‘On Ethical aspects of human tissue banking’, recommended only that under presumed consent systems, ‘doctors must ensure as far as possible that relatives or next of kin have the opportunity to express *the deceased person’s wishes*, and must take these into account’.⁴⁸

Reiterating that Council of Europe member states are free to consider these guidelines and recommendations or not (as in the case of hard opt out countries like Austria), we are not persuaded that ‘European and international’ instruments have accorded particular importance on a ‘principle’ that relatives’ views must be established by means of reasonable enquiries.

Nor are we persuaded that these instruments spell out whether it is the responsibility of relatives or authorities to contact the other to express or obtain consent to tissue or organ removal. The 1978 resolution gives member states wide latitude and little detailed guidance, and the 1998 Opinion speaks only to relatives expressing the deceased's person's wishes, not their own. Taken together, the two instruments serve to undermine the authority of the ECtHR's decision.

In sum, then, the question of whether Ms Elberte's right to respect for private life had been violated *does* turn to some degree on whether the Law operated on explicit or presumed consent. Determining the procedural quality of the Latvian Law cannot be performed without drawing in larger determinations about the substantive donation system in place. By steering clear of ruling on the legitimacy and scope of a presumed consent versus explicit consent system, the ECtHR decision's impact may be more profound and perplexing. Rather than an 'open and shut' arbitrariness case, the ECtHR has opened the door to serious doubt regarding the procedural adequacy of certain soft opt out consent systems currently in operation throughout the Council of Europe member states (a number, we note, that it is not insignificant), as well as opt in systems that allow some means for relatives to consent or object.

Countries such as Austria, which operate under a hard opt out (presumed consent) system that make it impossible for relatives to object to removal, would appear safe from judicial scrutiny under the Convention because they do not bother making any reference to relatives' wishes at all. Countries such as Spain that operate under one type of soft opt out system may be safe from judicial scrutiny under the Convention, because (presumably) they make it sufficiently clear in law that health professionals should consult with relatives prior to any tissue or organ removal. However, for soft opt out countries such as Belgium that make it incumbent on relatives to communicate with health professionals to rightfully object to

removal, the decision will carry special importance. It may be the case that Belgium's current law sufficiently stipulates that the duty to communicate falls on relatives rather than on health professionals and sufficiently describes how to give proper effect to a right to object – but this is an open question.

Finally, although the Latvian Government failed to raise the question, we certainly wonder whether a relative's right to object – read here in light of the decision as a right of a relative to express his or her *own autonomous judgement* whether tissue or organs of the deceased should be removed – can securely fit within an Article 8 'right to respect for private life', a right which, as noted in the concurring opinion of Judge Wojtyczek, increasingly seems to entail a general freedom of *action*.⁴⁹ Even if the concept of private life is a 'broad term not susceptible to exhaustive definition',⁵⁰ must the ECtHR not at some point engage in a discussion of its legal contours? As Moreham remarks, 'The breadth of the private life interest, combined with the Court's reluctance to identify either categories into which "private life" can be divided or specific examples on which its decisions are based, makes it difficult to ascertain exactly what domestic courts should be taking into account when developing domestic law.'⁵¹

The position of the ECtHR so far has been to embark on a steady campaign of expansion. *Elberte* tracks a growing judicial recognition of the legal interests that relatives have in the bodies of their relatives, and indeed the ECtHR cited its other judgements that have already confirmed this, such as the return of the bodies of children.⁵² The right to respect for private life is no longer merely a negative right that an individual holds against the State; it is now a positive right that bestows upon an individual the power to act and, in this case, apparently to consent to the means of disposal of another person's body.⁵³ Meaningful exploration of the bounds of private life so as to contain this hitherto generic legal interest under Article 8 has been lacking and is needed.

It is needed because we are concerned with where the reasoning of *Elberte* may lead. The consent of a relative is now linked to the right to respect for private life, which itself can now oblige action rather than inaction. But how much procedural detail must countries have in their domestic laws to satisfy a relative's right to respect for private life, which through its positive manifestation now entails a *right* of a relative to exercise an autonomous and authoritative decision on the potential interference with a deceased's body? Should we continue to rely on this individualist model of autonomy 'for regulating what is essentially a matter of interpersonal relationships?'⁵⁴ What impacts on society might result from this expanding link between human rights and individualist autonomy? And what is the extent of the positive duties placed on competent authorities to communicate with different relatives and weigh their potentially conflicting opinions?

Council of Europe member states have entered into a new era of legal uncertainty. Indeed, what concerns us most is that this decision may serve as precedent to future claims – even in opt in jurisdictions with no mention in domestic law of relatives and consent – of an individualist autonomous human right of a close relative to express authoritative judgement over the possible removal of a deceased relative's bodily tissue or organs. If opt in jurisdictions already allow *in practice* in some instances relatives to override even the express wishes of the deceased, how far removed are we from a court finding that, even if not articulated expressly in law, through a country's permissive actions, they are estopped from denying the relative's stand-alone so-called right to consent? *Quo vadis* the new balance between the right to respect for private life and the lifesaving benefits of tissue and organ transplantation, a matter we dare say may invoke other Convention Articles: the right to life and freedom from discrimination.⁵⁵

Conclusions

What lessons can we draw from this case? For one, we learn that law continues to struggle with death and donation. There are never easy solutions in matters relating to tissue and organ transplantation, the interests of the deceased, the interests of the deceased's relatives and the interests of society in improving others' health. No sooner than the final chapter of one person's life ends do many tragic epilogues begin in a common but varying tale of multiple persons claiming and deciding upon interests in body, soul and patrimony. In *Elberte*, we learned that the law of one country failed to give proper effect to a right that it created for those closest to a deceased. We also learned that its failure in so doing was a fundamental failure – a human rights failure. Certainly many facts in this case are disturbing, and the aura of a 'bodysnatcher' storyline permeates the text.

But this cannot be a lesson that satisfies. To be sure, Ms Elberte's Article 3 claim of inhuman or degrading treatment was rightfully successful. Latvian state authorities treated both the deceased Mr Elberts and Ms Elberte with an unacceptable amount of disrespect – the latter over many years. That Ms Elberte suffered shock and a high degree of emotional suffering would surprise few. Yet the acceptance of the Article 8 claim of a violation of her right to respect for private life does not instruct so much as obscure. Citizens in the member states bear witness to the ever-expanding juridical nature of private life, whilst the norms of privacy undergo profound change in a socially mediated society. For their part, member state legislatures bear caution as to the putative relation(al) interests private life may embody in law and how these interests relate to consent. Puzzling and somewhat ironic it is, however, that Ms Elberte's claim was not accepted by the ECtHR as a part of family life – which is necessarily relational – but rather as her own individual private life. The citizen is the recipient of a mysterious, mixed message about relationality that remains firmly grounded in individualism. The ultimate lesson may be that the ECtHR's decision reflects our own

collective ambivalence about, and on-going quest to shape, our rights, duties and roles as individual, relative and citizen in an at once connected and separated 21st century.

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2. *Elberte v. Latvia* (Application no. 61243/08) [2015] ECHR 1.
3. A similar case that also dealt with a car accident, questionable removal of tissue/organs, and the Latvian domestic Law on the Protection of the Body of Deceased Human Beings and the Use of Human Tissues and Organs in Medicine, was decided by the ECtHR six months earlier in June 2014. See *Petrova v. Latvia* (Application no. 4605/05) [2014] ECHR 805. In this case, the applicant was the deceased’s mother, who claimed that she had not been informed about the possible removal of her son’s organs for transplantation purposes and therefore had been unable to exercise certain rights established under domestic law. The ECtHR ruled that the Latvian law as applied at the time of the death of the applicant’s son had not been formulated with sufficient precision and did not afford adequate legal protection against arbitrariness. In this article, we focus the discussion squarely on *Elberte*, as it is the more recent and authoritative of the two on Article 3 and Article 8 of the European Convention on Human Rights as they relate to tissue and organ donation. As the ECtHR notes in *Elberte* at para. 140, ‘there are considerable differences between the present case and the [...] *Petrova* case as concerns the scale and magnitude of the organ or tissue removals.’ Yet in both cases, the ECtHR took note of ‘certain structural deficiencies which have prevailed in the field of organ and tissue

transplantation in Latvia’, and both decisions focus squarely on the quality of the domestic law and whether it was formulated with sufficient precision to be sufficiently clear and foreseeable in its application. Unlike in *Elberte*, however, in *Petrova*, the ECtHR, at para. 102, ‘having regard to the finding relating to Article 8’ found it unnecessary to examine whether there was also a violation of Article 3 of the Convention. Two reasons explain this. First, the ECtHR found that a separate claim for a violation of Article 3 must establish suffering that is of a character distinct from the distress caused by a violation of Article 8 (this was not the case in *Petrova*). Second, to assess the distinctness of suffering under Article 3, ‘relevant elements include the closeness of the familial bond and the way the authorities responded to the relative’s enquiries.’ See *Elberte* at para. 137.

4. There is a tremendous amount of literature (and academic debate) on relational autonomy and its various procedural, substantive, causal and constitutive meanings. See Catriona MacKenzie and Natalie Stoljar, eds., *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self: Feminist Essays on Autonomy, Agency and Social Self* (New York, OUP, 2000); Jennifer Nedelsky, *Law’s Relations: A Relational Theory of Self, Autonomy and Law* (New York, OUP, 2011); Jocelyn Downie and Jennifer J. Llewellyn, *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver, University of British Columbia Press, 2012). Due to space constraints in this article, we cannot develop a full discussion of relational autonomy. Generally, relational autonomy has been understood to represent feminist reconceptualisations of the notion of (atomistic) autonomy. For the purposes of this article, we view relational autonomy as meaning the capacity for a socially, culturally and historically embedded individual to exercise self-determination in and through networks of relations with others.
5. *Elberte*, emphasis added, para. 44.
6. Ms Elberte’s third claim relied on Article 13 of the European Convention on Human Rights (ECHR), in connection with the fact that there were several possible interpretations of the Law. Article 13 of the ECHR states, ‘Everyone whose rights and freedoms as set forth in this Convention are violated shall have an effective remedy before a national authority notwithstanding that the violation has been committed by persons acting in an official capacity’. The ECtHR ruled that as it had already examined the lack of clarity of the Law under Article 8 in its decision, it did not consider it necessary to examine the complaint separately under Article 13.
7. Article 3 of the ECHR states, ‘No one shall be subjected to torture or to inhuman or degrading treatment or punishment.’
8. *Elberte*, para. 137.
9. *Çakıcı v. Turkey* (Application no. 23657/94) [1999] ECHR 43 at para. 98; *Mubilanzila Mayeka and Kaniki Mitunga v. Belgium* (Application no. 13178/03)

[2006] ECHR 1170 at para. 61; *M.P. and Others v. Bulgaria* (Application no. 22457/08) [2011] ECHR 1920 at paras. 122-124.

10. *Elberte*, para. 88.
11. *Op. cit.*, para. 89
12. The court cited *Hadri-Vionnet v. Switzerland* (Application no. 55525/00), 14 February 2008. Elsewhere, in *Niemietz v. Germany* (Application no. 13710/88) [1992] ECHR 80, the ECtHR held at para. 29 that Article 8 includes the right to establish and develop relationships with other human beings, suggesting a social element to private life ('The Court does not consider it possible or necessary to attempt an exhaustive definition of the notion of "private life". [...] Respect for private life must also comprise to a certain degree the right to establish and develop relationships with other human beings.').
13. *Elberte*, para. 89.
14. *S. and Marper v. the United Kingdom* (Applications nos. 30562/04 and 30566/04) [2008] ECHR 1581.
15. *Elberte*, para. 104. Article 8(2) of the European Convention on Human Rights stipulates that an interfering measure must not only be 'in accordance with the law', it must also serve one of the legitimate aims specified in Article 8(2) (namely interests of national security, public safety or the economic well-being of the country, the prevention of disorder or crime, the protection of health or morals or the protection of the rights and freedoms of others) and the interfering measure must be 'necessary in a democratic society'. Interestingly, the European Court of Human Rights did not discuss the latter two criteria in its decision.
16. *Op. cit.*, para. 114.
17. *Op. cit.*, para. 113.
18. *Op. cit.*
19. M. Strathern, 'Partners and Consumers: Making Relations Visible' *New Literary History*, 22(3) (1991), pp. 581-601, at p. 591.
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 25. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York, OUP, 2001), p. 57.
 26. See fn 4.
 27. Katri Lõhmus, *Caring Autonomy: European Human Rights Law and the Challenge of Individualism* (Cambridge, CUP, 2015).
 28. R. Young, 'Informed Consent and Patient Autonomy', in Helga Kuhse and Peter Singer, eds., *A Companion to Bioethics*, 2nd ed. (London, Wiley-Blackwell, 2009), pp. 530-40.
 29. Beauchamp and Childress, *Principles*, p. 59.
 30. Douglas and Cronin, 'The Human Transplantation (Wales) Act 2013', p. 328.
 31. Op. cit., p. 325.
 32. R. Brownsword, 'The Cult of Consent: Fixation and Fallacy' *King's College Law Journal* 15(2) (2004), p. 233.
 33. Op. cit.
 34. Op. cit.
 35. Human Tissue Act 2004 and Human Tissue (Scotland) Act 2006. The Human Transplantation (Wales) Act 2013 introduced a 'soft opt out' system of organ and tissue donation in Wales whereby adults dying in Wales (with certain exceptions) are

‘deemed’ to consent to donation unless evidence of their objection is produced. See Douglas and Cronin, ‘The Human Transplantation (Wales) Act 2013’. However, Douglas and Cronin note at pp. 347–348 that there is ‘wide latitude’ in the new Act in ‘not proceeding [with tissue or organ removal] in the presence of family distress’, and thus ‘family objection and opposition, based on a wide interpretation of “distress”, will continue to be the effective regulator of organ donation rather than judicial rulings, which is regrettable’.

36. J. Kenyon Mason and Graeme T. Laurie, *Mason & McCall Smith’s Law & Medical Ethics*, 9th ed. (Oxford, OUP, 2013), p. 585. Opt in systems may recognize situations where the wishes of the deceased should be overridden by relatives. See NHS Blood and Transplant, *Organ and tissue donation – your questions answered* (‘There may, nevertheless, be cases where it would be inappropriate for donation to go ahead.’). Available at: <http://www.organdonation.nhs.uk/how_to_become_a_donor/questions/> (accessed 19 May 2015); Human Tissue Authority (HTA), Code of practice 2 – Donation of solid organs for transplantation, para 102 (‘Once it is known that the deceased person consented to donation, the matter should be discussed sensitively with those close to the deceased. They should be encouraged to recognize the wishes of the deceased and it should be made clear, if necessary, that they do not have the legal right to veto or overrule their wishes. There may nevertheless be cases in which donation is considered inappropriate and each case should be assessed individually’). Available at: <https://www.hta.gov.uk/sites/default/files/Code_of_practice_2_-_Donation_of_solid_organ_for_transplantation.pdf> (accessed 19 May 2015).
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40. M. Brazier, ‘Organ Retention and Return: Problems of Consent’ *Journal of Medical Ethics* 29(1) (2003), pp. 30-33.
41. The European Court of Human Rights has observed that ‘[t]he notion of personal autonomy is an important principle underlying the interpretation of [Convention] guarantees’. See *Goodwin v. United Kingdom* (Application no. 28957/95) [2002] ECHR 588, para 90. See also Lõhmus, *Caring Autonomy*.
42. *Elberte*, para. 110. (‘The issue before the Court in the present case is not the general question of the whether [Latvia] should provide for a particular consent system.’). We

wonder whether the troubling questions surrounding consent we discussed in the previous section of this article might have played some role in the European Court of Human Rights' reluctance to engage the issue.

43. Op. cit., para. 92 ('The applicant was of the opinion that the experts should have enquired whether the closest relatives had agreed or objected to tissue removal and that they had been under an obligation to do so under the ... provisions. ... [The applicant also was of the opinion that] the 2004 amendments to the Law demonstrated that previously the system of "explicit consent" had prevailed.').
44. Op. cit., para. 97 ('The Government argued that under sections 4 and 11 of the Law only "an absence of any objection by the deceased person expressed prior to his death or an absence of explicit objection by [the closest relatives] expressed prior to the tissue removal" had been required. The Government thus argued that the system of "presumed consent" had been operating in Latvia at the material time.').
45. Op. cit., para. 113.
46. Op. cit.
47. Council of Europe, Committee of Ministers, Resolution (78) 29 on harmonisation of legislations of member states relating to removal, grafting and transplantation of human substances (11 May 1978), available at [http://www.coe.int/t/dg3/healthbioethic/Texts_and_documents/Res\(78\)29E.pdf](http://www.coe.int/t/dg3/healthbioethic/Texts_and_documents/Res(78)29E.pdf) accessed 19 May 2015. Emphasis added.
48. European Group on Ethics in Science and New Technologies (EGE), 'Opinion no. 11: Ethical aspects of human tissue banking' (21 July 1998) *Politics and the Life Sciences*, 17(2) (1998), pp. 203-8. Emphasis added.
49. *Elberte*, concurring opinion of Wojtyczek J at para. 4.
50. *Elberte*, para. 89. See also *Peck v. United Kingdom* (Application no. 44647/98), [2003] ECHR 44.
51. N.A. Moreham, 'The Right to Respect for Private Life in the European Convention on Human Rights: A Re-examination' *European Human Rights Law Review* 44(1) (2008), p. 45.
52. *Pannullo and Forte v. France* (Application no. 37794/97) [2001] ECHR 741. See also Moreham, 'The Right to Respect for Private Life'.
53. In *Dickson v. United Kingdom* (Application no. 44362/04) [2007] ECHR 1050, the ECtHR held at para. 70 that 'although the object of Article 8 is essentially that of protecting the individual against arbitrary interference by the public authorities [...] there may be positive obligations inherent in an effective respect for private and

family life. These obligations may involve the adoption of measures designed to secure respect for private and family life even in the sphere of the relations of individuals between themselves. The boundaries between the State's positive and negative obligations under Article 8 do not lend themselves to precise definition. The applicable principles are nonetheless similar. In particular, in both instances regard must be had to the fair balance to be struck between the competing interests.' See also Robin C.A. White and Clare Ovey, *Jacobs, White & Ovey: The European Convention on Human Rights*, 5th ed. (Oxford, OUP, 2010), p. 401 ('What does emerge is that the distinction between positive and negative obligations in this context [private life] is becoming increasingly blurred, and that the procedural dimension to decision-making affecting rights within the ambit of private life is taking on greater importance. [...] Procedures in this context must offer an effective means for national authorities to consider and reflect upon the private life dimension to situations ranging from artificial insemination to permits for large-scale projects with the capacity to harm the environment.').

54. Lõhmus, *Caring Autonomy*, p. 1.
55. Article 2(1) of the ECHR states in part, 'Everyone's right to life shall be protected by law.' Article 14 of the ECHR states that 'The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status'.