Conjoined Twins in Adulthood: Case Studies, Ethical Challenges, and Sociocultural Perspectives

Introduction

Conjoined twins (also historically called "Siamese twins") are identical twins whose bodies are physically fused from birth. This phenomenon is extremely rare, occurring roughly in 1 in 50,000 to 200,000 births 1. A majority are stillborn or die shortly after birth; only an estimated 7.5% survive to a point where surgical separation might be attempted 2. Advances in neonatal care and surgery have improved survival and separation outcomes for many conjoined twins, yet in some cases the twins remain joined throughout life, either because separation is medically impossible or by choice due to the risks and trade-offs involved. This article examines adult conjoined twins who have remained physically joined, exploring documented case studies of prominent pairs, the medical types of conjoinment and how that affects separability, the ethical and medical reasoning behind non-separation, the psychosocial dynamics of living an inseparable life, and the ways such twins are portrayed and navigate their identities in public discourse.

Documented Cases of Adult Conjoined Twins

A number of conjoined twin pairs have defied the odds by surviving into adulthood without surgical separation. Their life histories provide insight into the medical and social realities of living permanently joined to one's twin. Below we review several prominent cases, both historical and modern, highlighting each pair's background, physical configuration, and daily life.

Chang and Eng Bunker (1811–1874)



Chang and Eng Bunker in the mid-19th century. Chang and Eng were perhaps the most famous conjoined twins in history, giving rise to the term "Siamese twins." Born in Siam (Thailand) in 1811, they were connected by a band of flesh at the lower chest (xiphopagus type) and shared a fused liver ³. Their connection was relatively small – a ligament at the sternum – and they had mostly separate organ systems, but they did share some circulation such that a serious event in one could fatally affect the other ⁴. In fact, when Chang died unexpectedly of a blood clot in 1874, Eng passed away just a few hours later as he hemorrhaged into his brother through their shared circulatory network ⁵ ⁶. In an era before advanced surgical techniques, separation was not pursued; ironically, modern surgeons have noted that Chang and Eng could likely have been safely separated by today's methods ⁷.

Despite their permanent union, Chang and Eng led remarkably "ordinary" adult lives for their time. After spending their youth on tour as a sideshow attraction, the twins eventually settled in North Carolina, became naturalized U.S. citizens, and achieved financial independence ⁸. They married two sisters and between them fathered over 20 children. To accommodate family life, they kept two separate households – spending alternating nights at each home – thereby asserting a degree of individual routine despite their physical inseparability ⁹. By all accounts, they cultivated their own personalities and roles: each had his own farm and family, and they took turns literally "leading" when walking or traveling. Their ability to adapt allowed them to blend into society as respectable landowners and family men, which became part of the public narrative of wonder—that two men joined in body could nonetheless live so conventionally ¹⁰ ¹¹. Their story, however, also illustrated the inherent fragility of their physical bond: the conjoined life that had enabled their fame and family meant that ultimately their deaths were intertwined as well ⁵.

Daisy and Violet Hilton (1908–1969)



Daisy and Violet Hilton (center) in a 1920s promotional photo, reflecting their brief Hollywood fame. The Hilton sisters were British-born conjoined twins who lived to age 60 without separation. They were pygopagus twins (joined at the lower back and buttocks), sharing blood circulation and some lower digestive organs, but with separate heads, torsos, and legs. Exploitation and resilience marked their lives. Their birth mother's midwife informally adopted and essentially "owned" them as infants, exhibiting them as curiosities

in carnivals from childhood ¹². Under various handlers, Daisy and Violet spent their early lives on tour in Europe and America, often kept isolated except when on display. By 1931, the sisters had had enough and successfully sued for emancipation from their abusive managers ¹³.

Once free, the Hilton twins achieved modest success on the vaudeville circuit. They played musical instruments and danced, and even appeared as themselves in Tod Browning's 1932 cult-classic film *Freaks* ¹⁴. They published an autobiography *The Lives and Loves of the Hilton Sisters* in 1942, seeking to tell their own story ¹⁴. Despite their talents, public appetite for "freak show" acts waned after World War II, and opportunities dried up. In 1951, they starred in a B-movie melodrama *Chained for Life* (a fictional plot loosely inspired by their lives), but during its publicity tour their new manager abandoned them, leaving the twins stranded in Charlotte, North Carolina ¹⁵. In order to survive, Daisy and Violet took up work as grocery store clerks – a poignant return to ordinary anonymity for two women who had once been international attractions. In January 1969, the 60-year-old sisters died of Hong Kong flu, succumbing within days of each other, presumably due to their shared circulatory system (one twin likely died first, leaving the other no chance of survival alone) ¹⁶. The Hilton sisters' life story highlights both the extreme social marginalization conjoined twins have faced and their personal agency: they fought for their independence in court and briefly succeeded in living on their own terms, yet ultimately remained literally and figuratively "chained" to each other by circumstance and biology.

Ronnie and Donnie Galyon (1951–2020)

Ronald and Donald Galyon were American conjoined twins who achieved fame late in life as record-holders. Born in 1951, they were thoraco-omphalopagus twins joined from the chest to the lower abdomen, facing each other – essentially fused from sternum to groin. Each had two arms and two legs, but they shared a single lower digestive tract and other organs, making separation infeasible. Doctors deemed any separation attempt too high-risk early on, so the brothers remained conjoined "as they were born" for the entirety of their 68 years ¹⁷. In childhood, Ronnie and Donnie helped support their family by appearing in carnival sideshows, much as Chang and Eng and the Hiltons had done ¹⁸. They traveled for years as a sideshow act in Latin America and the U.S., drawing curiosity and income, until retiring from public exhibition in 1991 to live a quieter life in their hometown of Dayton, Ohio ¹⁸.

Remarkably, the Galyon twins became the **longest-living conjoined twins on record**, surpassing Chang and Eng's lifespan. In 2014, at age 63, they earned a Guinness World Record for longevity ¹⁹ ²⁰. They eventually reached 68 years old, passing away in 2020 of natural causes related to age and organ failure. According to family, in their final decade the brothers' health declined and they required full-time care; the local community even fundraised to help modify their living space so that Ronnie and Donnie could remain at home with their younger brother caring for them ²¹ ²². Personality-wise, the twins were known to be quite different individuals despite literally sharing a body: one was described as easy-going and the other more temperamental, and they even held opposing political opinions, which made for lively internal debates ²³. This testified to their distinct identities, something they themselves were keenly aware of. Their brother Jim noted that despite the hardships of being eternally bound together, "they couldn't ask for anything more" than the full life they led ²⁴ ²⁵. The Galyons' story underscores that with supportive care (and avoiding surgical risks), conjoined twins can reach old age, and that two minds can maintain individuality even in one fused body.

Lori and George Schappell (1961–2024)

Lori and George Schappell (born Lori and Dori Schappell) were craniopagus twins from Pennsylvania who, until their recent passing in 2024, were among the oldest living conjoined twins in the world 26 . They were joined at the head, with an attachment of their skulls and some brain tissue (about 30% of their brain matter was shared) 27 28 . Each twin had a separate body and brain hemisphere, but their skulls were partly fused and they shared blood vessels in the brain, making surgical separation impossible without fatal risk 29 . One twin (Lori) was able to walk normally, whereas George (born Dori) had spina bifida and underdeveloped lower limbs, requiring a custom wheeled stool for mobility. Impressively, Lori would push and steer George's wheeled seat, demonstrating a lifetime of physical cooperation in daily tasks 28 30 .

The Schappell twins lived into their early 60s, pursuing distinct personal interests and identities. In 2007 Dori came out as transgender and adopted the name George; he also at times used the stage name "Reba" when performing as a country music singer [31]. George became an award-winning country/gospel singer (with several recordings and performances on television), while Lori developed her own hobbies (such as competitive bowling) 32 33. They emphasized that being conjoined did not eliminate their need for privacy or individuality. In a documentary interview, the twins demonstrated how they arrange "alone time" despite never physically separating: they maintained two separate bedrooms and would alternate which twin got to have their own space on a given night ³⁴ ³⁵ . "Just because we cannot get up and walk away from each other doesn't mean we cannot have solitude," Lori explained in one interview 34. The twins developed ground rules to respect each other's personal space and social lives - for example, when George (as Reba) rehearsed music, Lori would mentally "tune out" to give him focus, and each refrained from interrupting the other during personal activities 32 34. This mutual respect enabled them to hold jobs (they worked together at a hospital in clerical roles) and manage relationships with friends. The Schappells' longevity was notable; at 62 years old they set a Guinness World Record as the oldest living female conjoined twins 36. Their recent deaths (within hours of each other, as often happens with shared vital circulation) marked the end of a truly extraordinary shared life. Lori and George's experiences show how conjoined twins can defy social expectations: they challenged assumptions about gender (in George's case), carved out independent identities, yet also exemplified the deep cooperation and bond required to thrive while literally attached together.

Abigail and Brittany Hensel (1990- present)

Perhaps the best-known contemporary conjoined twins, Abby and Brittany Hensel are dicephalic parapagus twins – meaning they have two heads side-by-side on one torso. Born in 1990 in the United States, the Hensel sisters share a single fused body from the neck down, with each twin controlling one side. They have individual vital organs in the upper body (each has her own heart, lungs, stomach, and spinal cord) but share many lower-body organs including a liver, one set of intestines, one bladder, and one set of reproductive organs ³⁷ ³⁸. Each twin can only feel sensations on her half of the body ³⁹. Remarkably, Abby and Brittany coordinate their movements so fluidly that they can walk, swim, ride a bicycle, and even drive a car together – activities that require seamless bilateral coordination ⁴⁰ ⁴¹. They each obtained a driver's license after both had to individually pass the driving test, and when driving Abby operates the pedals and gear shifts while Brittany controls the turn signals, with both sharing the steering wheel ⁴² ⁴³. Such feats highlight the twins' lifelong adaptive collaboration.

Medically, separation was never attempted in the Hensels' case because it was judged too complex and risky – any operation would have meant sacrificing major organs and likely leaving at least one twin with

fatal deficits. Their parents were advised early that the girls were "inseparable," and as the twins grew it became clear that they could live a full life without separation. The family decisively declined further medical interventions beyond routine care, not wanting the girls to be treated as research subjects or surgical experiments 44 45. Abby and Brittany themselves have consistently expressed that they have never wished to be separated 46. "We wouldn't get to do all the things that we do - play sports, run, or travel – if we were apart," they noted, emphasizing that their shared life is their normalcy 47. Now in their mid-30s, the Hensel twins have achieved milestones as two distinct individuals in one body: they graduated college, became licensed teachers (together teaching a single elementary classroom, effectively doing the work of one teacher with two minds), and even navigated personal relationships. In 2021, Abby Hensel married her longtime boyfriend, becoming perhaps the first conjoined twin in modern history to wed, while Brittany remains single by mutual agreement 48. The twins have not publicly discussed how marriage or future motherhood would work for them, preferring to keep such matters private. They maintain a largely low-profile life in Minnesota, after a period of media attention that included a TLC reality series in 2012 and an early appearance on The Oprah Winfrey Show in 1996. When they do step into the public eye, it is often to educate others about their condition. For example, in 2023 they shared a video explaining the intricacies of their anatomy and how their bodies are a "remarkable blend" of separate and shared organs 49 38. By openly discussing how they function, the Hensels hope to demystify the concept of living as conjoined twins, while also asserting their desire for privacy and respect in daily life 45. Their story powerfully demonstrates that two people can live a rich, coordinated life while sharing one body, and it continues to intrigue both the medical community and the public at large.

Types of Conjoinment and Implications for Separation

Conjoined twins are classified by the location at which their bodies are fused, and this anatomical configuration heavily influences whether surgical separation is feasible. The major types of conjoinment include: **thoracopagus** (joined at the chest), **omphalopagus** (joined at the abdomen, often considered a subset of thoracopagus), **pygopagus** (joined at the lower back or buttocks), **ischiopagus** (joined at the pelvis/hips), and **craniopagus** (joined at the skull/head). Rarer variants and asymmetric cases (such as parasitic twins) also exist. Each type presents unique medical considerations:

- Thoracopagus (Thoraco-omphalopagus) This is the most common form, accounting for up to ~40% of cases (often grouped with omphalopagus) ⁵⁰ ⁵¹. Thoracopagus twins are face-to-face, fused from the upper chest down to the navel. They almost always share a heart or at least the great vessels, as well as the liver and upper abdominal organs ⁵¹ ⁵². *Impact on separation:* Shared cardiac anatomy is a critical issue if twins are conjoined at the heart, especially at the ventricular level (pumping chambers), successful separation is essentially impossible with current medical technology ⁵¹. In fact, no twins sharing a single functional heart have both survived separation ⁵¹. If each twin has an independent heart and only the liver or chest wall are connected, separation can be attempted and often is successful (since the liver can regenerate and be divided between two bodies). The presence of separate versus fused organ systems in thoracopagus twins largely determines prognosis: "If they have separate sets of organs, chances for surgery and survival are greater than if they share the same organs... as a rule, conjoined twins who share a heart cannot be separated" ⁵³ ⁵⁴.
- **Omphalopagus** Twins joined primarily at the abdomen (around the navel). They usually face each other and share the abdominal wall and often the liver, but typically have separate hearts and separate heads ⁵². Their gastrointestinal tracts may have some intersections (commonly a bridge of

liver tissue connects them, and sometimes portions of intestines are shared or entwined) 52 55. *Impact on separation:* Omphalopagus twins are considered among the least complex conjoinments to separate, provided each twin has complete sets of vital organs. Many successful separations have been done, especially if the shared organs are limited to the liver or bowel which can be surgically divided and reconstructed. These twins can often live independently post-separation with good outcomes, as long as any shared organ (like liver) is adequately apportioned or transplanted if necessary.

- **Pygopagus** Twins joined back-to-back at the sacrum and coccyx (lower spine and buttocks), comprising around 15–20% of cases ⁵⁶. They have separate upper bodies and heads, but their spines meet at the base. They often share portions of the lower gastrointestinal tract (e.g. a common rectum or anus) and sometimes the genital and urinary systems are fused ⁵⁶ ⁵⁷. *Impact on separation:* Separation is usually possible if each twin has adequate nerve and muscle control of the lower body after dividing the spinal connection. Surgical challenges include reconstructing the anus and genitalia for each twin if those were shared ⁵⁸ ⁵⁷. Many pygopagus twins have been successfully separated, especially when modern colostomy and reconstructive techniques are available. Those who remain conjoined (like Daisy and Violet Hilton) generally do so because separation was not attempted in their era or because the neurological link at the spine made it risky to split them.
- **Ischiopagus** Twins joined at the pelvis, often with the two bodies oriented side by side or end-to-end. This accounts for <5% of cases ⁵⁹ . Ischiopagus twins typically share the lower pelvic bones and may have a conjoined lower gastrointestinal and genitourinary system. They often have four legs between them, although some legs may be fused or non-functional ⁵⁹ ⁶⁰ . In some ischiopagus cases, one twin may be oriented upside-down relative to the other (so-called ischio-omphalopagus). *Impact on separation:* Pelvic conjunctions are complex but can sometimes be separated if each twin has sufficient organs. Often each twin will only have one functional leg after separation (if two of the four legs were shared or malformed) ⁵⁹ . The surgery must address shared urinary bladders or reproductive organs and ensure each twin retains or reconstructs continence. Outcomes vary widely depending on organ sharing; for instance, separation is far more difficult if they share a single set of kidneys or a spinal cord.
- **Craniopagus** Twins fused at the skull, making up about 2% of all conjoined twins 61 62 . They may be joined at the top, back, or side of the head. Craniopagus twins **always** share skull bone and the dura (brain covering); most share some venous blood circulation in the brain, and a minority even share brain tissue or neural structures. In many craniopagus cases, each twin has a separate brain but their cerebral blood drainage is interconnected (for example, they might share the superior sagittal sinus, a major venous channel) 63 . In rare instances like the Hogan twins in Canada, the brains are linked by a bridge of neural tissue, allowing some sensory information to pass between them (an extraordinary case where each twin can experience what the other sees or feels) 64 65 . *Impact on separation:* Separating craniopagus twins is among the most challenging procedures in neurosurgery. It often requires multiple staged operations to gradually reroute blood vessels and, if necessary, partition shared brain areas. Even so, the risk of one or both twins suffering brain damage or death is high. Historically, attempts to separate adult craniopagus twins have had very poor outcomes (e.g., the tragic 2003 case of Ladan and Laleh Bijani, 29-year-old Iranian sisters joined at the head, where both died from blood loss during separation) 66 67 . Successful separations have mostly been done in infancy or early childhood, when the brain has more plasticity to recover;

even then, one twin may suffer deficits if the vascular division is unequal. If craniopagus twins share significant brain tissue or a critical vein, surgeons may deem them non-separable. For those who remain conjoined into adulthood, such as Lori and George Schappell or Tatiana and Krista Hogan, it is either because separation was not medically safe or because the twins (or their guardians) chose not to risk the operation.

It is important to note that each conjoined twin case is unique. Within the broad categories above, there are wide variations in anatomy. Modern medical imaging (3D ultrasound, MRI, CT angiography) is used to map out shared structures in detail ⁶⁸ ⁶⁹. A multidisciplinary team must determine whether separation can be done **"with both twins surviving and with acceptable quality of life"**. If twins share a **vital organ** that cannot be divided or duplicated (such as a heart or brain), they are generally considered non-separable without sacrificing one twin ⁷⁰ ⁷¹. On the other hand, if each twin has the critical organs needed for independent life, even extensive fusions can sometimes be corrected in a lengthy surgery. The timing of separation, if pursued, is usually in infancy, as outcomes are better the younger the patients are (before their anatomies and dependence become more complex) ⁷² ⁷³. The result of these medical possibilities is that today relatively few conjoined twins reach adulthood still joined, compared to past centuries – typically only those for whom separation was deemed impossible or those who strongly preferred to stay together. These adult pairs face a distinct set of ethical and social considerations, as discussed in the following sections.

Ethical and Medical Considerations in Decisions Not to Separate

Deciding whether to separate conjoined twins involves complex ethical calculations, balancing the medical risks against questions of identity, autonomy, and quality of life. In cases where separation is technically achievable, doctors and families must consider if it *should* be done; conversely, when twins remain conjoined by necessity or choice, they and their caregivers face ongoing ethical decisions about how to manage life as a permanently fused unit.

Medical Risk vs. Benefit: The foremost medical consideration is whether separation can be accomplished safely. If an attempted separation would likely kill or irreparably harm one or both twins, the default ethical stance is usually to forgo surgery. For example, Ronnie and Donnie Galyon's doctors concluded early on that separating them (who shared many organs) would risk both lives with little chance of success, so nonseparation was the prudent course 17. Similarly, the Hensel twins' parents were told that separation in infancy was technically possible but carried significant risk and trade-offs (e.g. one twin might end up without vital organs). Seeing that the babies could grow and thrive conjoined, the parents chose not to pursue separation, a decision the adult twins have affirmed 44 46. In modern pediatric care, such decisions often involve hospital ethics committees and months of deliberation. Guidelines generally state that elective separation surgery is justified only if each twin's chance of survival and a decent life is improved by being apart 70 74. If separating means certain death for one twin (a so-called "sacrificial separation"), many ethicists and surgeons are uneasy proceeding unless that twin is already dying or severely compromised. Indeed, some bioethicists argue that sacrificial separations are fundamentally unethical because they intentionally end one life to possibly benefit another 71. This view was put to the test in the precedent-setting case of "Jodie and Mary" (Re A) in 2000, in the U.K. In that case, infant girls were joined at the pelvis; one twin (Mary) had no functional organs and survived only by parasitically sharing her sister's circulatory system. If left together, both would die within months; separation would save the healthier twin (Jodie) but definitely kill the weaker one. The twins' parents opposed the operation on religious grounds, unwilling to "play God" by actively ending Mary's life. The courts ultimately intervened

and authorized separation, even acknowledging it meant "the operation will condemn 'unviable' Mary to almost certain death" in order to give Jodie a chance at life 75 76. The judges agonized over essentially "choosing between two evils," framing it starkly: "Do we save Jodie by murdering Mary?" 77. They justified the decision as an act of necessity, not murder, allowing surgeons to proceed. As predicted, the surgery succeeded in saving Jodie, while Mary died immediately – a tragic outcome but one the court deemed ethically permissible to avoid the death of both 78 79. This case remains heavily debated in bioethics and law, illustrating how controversial the separation question can become when one twin's survival is pitted against the other's.

Autonomy and Consent: The ethical landscape shifts when conjoined twins reach an age or condition where they can express their own wishes. Autonomous decision-making is complicated in these situations – effectively two individuals must each consent to or refuse an intervention that will affect them both. Adult conjoined twins sometimes disagree with each other or with doctors about separation. An illustrative case is that of **Ladan and Laleh Bijani**, 29-year-old Iranian craniopagus twin sisters. In 2003, they insisted on undergoing a high-risk surgery to separate, despite warnings that it could be fatal [80] [67]. The sisters, both law graduates, yearned for independent lives and separate careers - one wanted to be a lawyer, the other a journalist 81. Their autonomy and desire for individuality led them to convince a surgical team in Singapore to attempt the unprecedented adult craniopagus separation. Tragically, after a 52-hour marathon surgery, both twins died from uncontrolled bleeding when surgeons divided a shared vein complex 66 67. The outcome sparked global ethical debate: some argued the doctors should never have risked such an operation, while others defended it on grounds of respecting the twins' personal autonomy and informed wishes 82 83. The Bijanis' case highlights the painful tension between the autonomy principle – honoring a competent adult's choices - and the medical principle of "do no harm." Most ethicists agree that adult conjoined twins have the right to refuse separation if they both are opposed. But if they desire separation, even at great risk, opinions diverge on whether surgeons are obliged to attempt it. In practice, very few adult separations have been done, partly because by adulthood the twins have adapted to their condition and major surgery carries higher mortality. Many adult twins, like the Hensels, state they would not choose to be separated even if it became possible, because their shared life is the only life they know and value 46.

Quality of Life Considerations: A core ethical question is whether conjoined twins can enjoy a "good life" if they remain together. Historically, some in the medical community assumed that separation is always the optimal goal, operating under the belief that two distinct bodies are necessary for personal well-being. Philosopher Jamie Bronstein critiques this stance, noting that while conjoined twins are two persons in the sense of having two independent minds, they are "trapped within a single organism in ways that crucially inhibit moral autonomy" 84 85. She argues that whenever physically possible, separation surgery should be done in infancy to give each twin the chance to develop as an autonomous individual 86 87. Bronstein and others point out difficult scenarios that permanent conjoinment raises: for instance, if adult conjoined twins have different desires about sexual relationships or childbearing, how can one exercise that choice without violating the other's bodily autonomy? If one twin committed a crime, how could society punish the quilty one without harming the innocent co-twin? If one twin wanted to pursue a drastically different life plan (career, location) than the other, their physical link severely constrains such independence 88. These hypotheticals underscore that remaining conjoined can limit certain aspects of freedom that most individuals take for granted 89 90. On the other hand, the lived experiences of many adult conjoined twins demonstrate that they often do report a high quality of life and a sense of wholeness as they are. "Adult conjoined twins often say they are content," Bronstein acknowledges 90, even as she maintains they have "less-than-optimal autonomy." Ethical analysis must therefore be careful not to impose an external value judgement that a conjoined life is inherently intolerable. As long as basic health and comfort can be

maintained, many twins thrive in their unique situation and may understandably resist being separated, especially if it would mean significant disability or the loss of their twin.

Who Decides and When: In pediatric cases, parents (in consultation with doctors and ethics boards) make the choice of whether and when to attempt separation. They must consider not only survival but also the potential future lives of their children. For example, if both twins can likely survive separation with some disabilities, is that better than growing up conjoined but fully mobile and healthy? There is no one-size-fitsall answer. Some parents opt for early separation to maximize each child's individuality; others, like the Hensels' parents, saw that their twins could function together and chose to preserve that wholeness 44. As conjoined twins grow up, they themselves become part of the decision-making process. Most separations happen in infancy or early childhood, but a few have occurred later. In those cases, hearing the twins' own preferences is crucial. The ethical ideal is to wait until the twins can assent or consent – but waiting too long can reduce the chances of success (as organs and shared systems become more entwined with age) 72. In an enlightening classification, medical experts sometimes categorize conjoined twin outcomes not just by anatomy but by fate: (1) those who die before or at birth, (2) those who survive only a short time if not separated, (3) those who survive long-term without separation, and (4) those who survive long-term after successful separation 91. Ethically, groups (3) and (4) present the dichotomy: if twins can survive long-term joined, should we accept that and support their life as a conjoined pair, or should we intervene for the possibility of having two "independent" lives? Increasingly, with improved surgical outcomes, the bias in medicine is toward intervention when it clearly offers better health or longevity prospects for the twins. But when intervention promises only marginal benefits or carries great hazards, the ethical choice may be to respect the integrity of the conjoined life. As one surgical ethicist put it, the goal is not separation at any cost, but rather maximizing the twins' combined well-being, whether that is as one unit or two.

Finally, ethical care for conjoined twins who remain together involves ensuring they receive the same dignity and rights as any persons. This includes access to education, employment, and healthcare without discrimination, and involving psychological support to help them navigate the challenges of joint life 92 93. Respecting their privacy and bodily autonomy in everyday matters is crucial – for instance, doctors must be mindful that any examination or procedure on one twin inherently involves the other, and thus medical consent is effectively a joint process. In summary, decisions not to separate conjoined twins are usually driven by medical reality (shared organs making it non-viable) or by a careful judgment that the risks outweigh the benefits. Those decisions carry forward a host of ethical responsibilities to support the twins' shared life, protect each twin's personhood as much as possible, and continually re-evaluate if circumstances change (e.g. if one twin's deterioration ever threatens the other's life, a dilemma can arise late in life about possible separation at that stage). Such scenarios are exceedingly rare and heartwrenching, reminding us that conjoined twins present some of the most profound ethical questions in medicine.

Psychological, Social, and Cultural Challenges and Strengths

Living as conjoined twins into adulthood entails navigating a world designed for "separate" people, which brings psychological and social challenges – but also fosters unique strengths and coping strategies. Adult conjoined twins and those who have studied them report a spectrum of experiences: from struggles for individual identity and privacy, to deep mutual understanding and resilience born of literally never being alone.

Identity and Personhood: A central psychological question is how conjoined twins conceive of themselves – as two distinct individuals, as two halves of a whole, or something in between. By definition, each twin has their own mind and personality, yet their life experiences are almost entirely shared. Many conjoined twins assert their individuality strongly. For instance, Abby and Brittany Hensel developed clearly different tastes, opinions, and even plans (they pursued different concentrations in college, one focusing more on math, the other on English). They often speak in the first-person plural ("we") when discussing mutual decisions, but will use their own names ("Abby thinks..., Brittany prefers...") when they have divergent views ⁹⁴ ⁹⁵. The Hensels refer to themselves as separate people who simply happen to share a body – a crucial distinction for how others should treat them. Lori and George Schappell likewise cultivated distinct identities: one sibling embraced a transgender male identity and musical career, the other did not, highlighting that they are not one fused personality but two people who made different life choices within the constraints of their physical union ³¹ ³².

However, conjoinment does impose a degree of *merged existence*. Psychologically, conjoined twins must negotiate boundaries of self and other from an early age in a way that no one else does. As children, some conjoined twins invent private languages or ways of communication, effectively operating like an intimate "dyad." It's reported that Tatiana and Krista Hogan, the craniopagus twins with a thalamic brain bridge, can literally share thoughts or know what the other wants without speaking ⁹⁶. Even for twins without neural linkage, decades of continuous companionship often yields an uncanny mutual intuition. The twins may develop what psychologists call *identity interdependence*, where each twin's sense of self is heavily defined by the constant presence of the other. Some twins describe feeling incomplete or lonely if momentarily separated (e.g. during medical tests) because they are habituated to an almost symbiotic daily existence. This can be a strength – a source of emotional security – but also a challenge if one twin yearns for more individuality.

In a few cases, significant personality clashes or mental health issues can arise, just as with any close siblings or cohabiting family members, but intensified by the inability to physically walk away. Conjoined twins report arguments like any siblings; the Hogan twins said, as preteens, "some days we don't like being together" and they would even try to pull apart during childhood tantrums ⁹⁷ ⁹⁸. Learning conflict resolution and compromise is thus an essential psychological skill for conjoined twins. Many pairs, like the Schappells, explicitly establish rules to respect each other's mental space – for example, using headphones if one wants to listen to different music, or scheduling solitary time in separate rooms (to the extent possible) ³⁴ ⁹⁹. The ability to cooperate is not just practical but psychological: it affirms to each twin that they are valued as an individual by the other, and not merely "stuck" together. Indeed, researchers have noted that conjoined twins often develop *complementary* personality dynamics to reduce friction – one might take on the role of the more assertive decision-maker if the other is more laid-back, thus avoiding constant power struggles ²³. This complementary teamwork, observed in pairs like Ronnie and Donnie Galyon (one being easygoing, the other more temperamental but acquiescing in certain domains) ²³, is a testament to the psychological adaptation conjoined twins achieve.

Social Challenges: Conjoined twins face numerous social hurdles, starting with the simple fact that they attract public attention wherever they go. Curiosity from strangers is a constant factor. Many twins recall being stared at or photographed in public, sometimes rudely. Abby and Brittany Hensel, despite their media-savvy efforts to normalize their image, admitted that they "absolutely hate" when people clandestinely take pictures of them in public, considering it a violation of their dignity ⁹⁵ ⁴⁵. They have been known to confront onlookers who don't ask permission, in order to assert that they are not objects on display but persons deserving respect. Historically, conjoined twins were often literally put on display –

Chang and Eng, the Hilton sisters, and the Galyon brothers all spent years being exhibited in circuses or sideshows. While this brought income and sometimes fame, it also reinforced a social perception of them as curiosities or "freaks," rather than ordinary individuals. In modern times, such overt exhibition is rare (and would be widely seen as exploitative), but vestiges of that attitude linger in how the media and public sometimes approach conjoined twins – focusing on their anomaly more than their personhood.

Another social challenge is **relationships** beyond the twinship. Forming friendships, romantic partnerships, or having a family can be complicated. Friends of conjoined twins effectively befriend two people at once, which can be wonderfully intimate (a close friend can become part of their tight-knit circle) but also intimidating for outsiders not sure how to interact with a duo that comes as a "package deal." Remarkably, many conjoined twins do form strong friendships and even romantic relationships. Chang and Eng Bunker marrying two women is a famous historical example 10, but it required some social accommodation – their wives were sisters, which perhaps made the unusual marital arrangement more acceptable within one family. The Bunkers managed a schedule so each husband had private time with his wife on alternating nights 9. In the present day, romance is still challenging but not impossible. Abby Hensel's marriage in 2021 indicates that at least one of the Hensel twins found a partner comfortable with their situation; Brittany, by all accounts, supported her sister's decision, and how the dynamics of that marriage work (intimacy, etc.) is kept strictly private, which is understandable. Other pairs, like Daisy and Violet Hilton, had romantic aspirations - Violet attempted to marry a partner in the 1930s, but sensationalistic press and legal barriers (questions of morality and bigamy, since technically Daisy would be "involved" by proximity) led to the marriage license being revoked. The sisters were heartbroken by this interference and lamented that they were denied a chance at normal love lives. Lori and George Schappell did not marry, but George (as Reba) dated men and once said he had fallen in love; Lori, by contrast, was more ambivalent about romance. Both acknowledged that any relationship would require extraordinary understanding from a third party, and that they themselves would have to navigate jealousy or awkwardness. In general, conjoined twins often emphasize that any potential partner would be effectively courting both, since, at minimum, the other twin's presence is a constant chaperone. This reality limits the pool of willing partners, and some twins choose not to pursue romance to avoid complications. Others, however, manage it by setting boundaries (e.g., the non-dating twin gives the couple as much privacy as possible, perhaps by wearing headphones or reading during their dates). These situations raise delicate questions about sexual autonomy and consent - an area not often discussed publicly by the twins, but one in which ethicists have shown interest (posing scenarios such as: If one twin consents to sexual activity and the other does not, is it even possible to proceed without effectively violating the non-consenting twin? 88). To date there are no universally accepted answers; most conjoined twins themselves keep such personal matters out of the spotlight, and case-by-case solutions are found privately.

Cultural and Societal Context: Culturally, conjoined twins have occupied a unique space, often seen through the lenses of myth, morality, and medical marvel. In some cultures historically, conjoined twins were viewed with superstition – as omens or divine signs – sometimes revered, but more often pitied or hidden. In 19th-century Western society, they became popular attractions in an era fascinated by "oddities." The legacy of the term *"Siamese twins"* (from Chang and Eng's origin) itself reflects an orientalist curiosity. Over time, there has been a shift: from viewing conjoined twins purely as sideshow spectacles or surgical problems, toward understanding them as persons with a disability that challenges our notions of individuality. Disability rights perspectives consider conjoined twins as an extreme case on the spectrum of human embodiment, urging society to accept that not all people fit the norm of one body/one person ¹⁰⁰

101 In recent decades, conjoined twins who speak publicly often attempt to *reframe* the narrative about themselves. The Hensel twins, for example, have been very active in media with the goal of demonstrating

normalcy. On a 1996 Oprah Winfrey interview that introduced them as children, they cheerfully showed viewers how they rode a bike and played, asserting they "were just the same as everyone else" except for being stuck together 102 103 . This approach continued in their 2012 reality TV series, which followed them through everyday milestones like getting a job, in order to portray them as relatable young women rather than medical oddities 104 105 .

Similarly, other twins have used documentaries or interviews to educate the public. Lori and George Schappell appeared on talk shows (e.g., the Jerry Lewis Telethon, *Howard Stern*, etc.) not simply for shock value but to discuss how they manage life and to advocate for understanding. George's music performances also challenged audiences to appreciate his talent first, not just his anatomy. Conjoined twins in the media face a paradox: they must draw attention to themselves to control their story, but that very act can feed public fascination. Some, like the Hogan twins' family, eventually withdraw from media once the twins are older, to give the twins control over their own narrative and avoid perpetual public scrutiny ¹⁰⁶

107. The Hogan family decided that after a certain point, there would be no more documentaries until the girls could decide for themselves, illustrating a protective approach to media exposure ¹⁰⁶

107.

Another cultural challenge is in legal and institutional recognition: Are conjoined twins treated as two people or one in various situations? In school systems, they are of course two students (with one seat perhaps modified); in legal documents, they have separate birth certificates and identities. But there have been quirky issues, such as how to count them for airline seating (usually they require only one ticket since they use one seatbelt), or how they are paid at work (the Hensels negotiated one salary since they jointly do the work of one teacher, but presumably split it behind the scenes, and they had to clarify that they count as two full teaching licenses in one classroom) ¹⁰⁸. Socially, many conjoined twins and their families end up becoming self-advocates and educators by necessity, paving the way for greater accommodation. The academic and medical communities now publish not only surgical case reports on conjoined twins, but also studies on the psychosocial development of conjoined children and how best to support them and their families ¹⁰⁹. For example, conjoined twins often require careful coordination of care – both twins need to be present for each other's medical appointments, therapy sessions, etc., which can be exhausting. Mental health support is recommended to help them deal with stress, especially if one twin falls ill or if their interests conflict ⁹² ¹¹⁰.

Despite these challenges, conjoined twins frequently demonstrate exceptional adaptive strengths. By adulthood, those who remain together have typically developed robust coping mechanisms and a positive outlook about their lives. Many report that the presence of their twin is a source of comfort and that they wouldn't want to live any other way. "We've always been like this, so we don't know different," is a common refrain that conveys contentment with their condition. The mutual reliance can also breed profound empathy and emotional support – each twin knows the other literally inside-out. In interviews, twins often finish each other's sentences or provide reassurance and humor to each other. The bond can be a tremendous psychological asset in facing external adversity. Furthermore, conjoined twins can achieve a sense of *shared accomplishment* that is unique: everything they do, they do together. For example, Abby and Brittany's successful co-teaching career is not just a personal achievement but a joint triumph of teamwork and sisterhood. Such successes challenge conventional notions of independence, suggesting that *interdependence* can be equally fulfilling.

From a cultural standpoint, conjoined twins provoke deep questions about the nature of self and relationship. They have inspired art, literature, and philosophical inquiry. Some view them through a lens of unity – almost a living symbol of cooperation – whereas others initially react with pity or morbid fascination.

But as society becomes more informed, the narrative is shifting toward celebrating conjoined twins' personhood and resilience. Conjoined twins themselves, when empowered, often choose to engage with the public to demystify their lives and assert their identities beyond their anatomy. As Helena Franzén, a disability historian, notes in her study of media attitudes, twins like the Hensels intentionally perform "normality" in media appearances to counter preconceptions, emphasizing the activities they *can* do and the ordinary aspects of their lives 111 105. This conscious framing helps redefine public discourse: instead of seeing conjoined twins as tragic or freakish, audiences are invited to see them as *people with extraordinary bodies but otherwise ordinary desires and rights*.

Representation in Media and Public Discourse

The public fascination with conjoined twins has a long history, and the way these twins are represented in media and popular discourse has significant implications for their privacy and identity. Over the centuries, conjoined twins have been portrayed variously as medical curiosities, prodigies, monsters, or inspirational figures. Examining this representation offers insight into societal attitudes and the twins' own agency in shaping their narrative.

Historical Sideshow Narratives: In the 19th and early 20th centuries, conjoined twins were most often seen on the carnival and freak show circuit. Chang and Eng Bunker's early fame came from exhibitions arranged by promoters who touted them as exotic wonders from Siam 112. Audiences paid to gaze at their connected bodies; in response, Chang and Eng learned to present themselves in a dignified manner dressing in suits, speaking in English—both to satisfy curiosity and to command respect. The twins astutely took control of their touring business in adulthood, using self-display as a livelihood while also dispelling myths (for example, demonstrating they were intelligent, "civilized" gentlemen rather than wild creatures) 10 . In Europe and America, newspapers and posters often emphasized the sensational aspects ("Siamese Twins!") but also fed the narrative of their normalcy offstage (reporting on their marriage and domestic life) as a further source of astonishment 8 113. Daisy and Violet Hilton likewise were marketed with a mix of allure and pathos - advertised as having "two hearts but one soul" or being "the eighth wonder of the world." Their vaudeville acts were popular, but behind the scenes they struggled against managers who literally treated them as property 114. The 1932 film Freaks featured the Hilton sisters in a sympathetic light (as part of a sideshow troupe who find love and friendship), yet the very title "Freaks" underscores how they were categorized in pop culture. The twins later tried to control their image by authoring an autobiography and starring in Chained for Life (1950), a film that dramatized the ethical dilemma of one conjoined twin accused of murder, playing on the notion of inseparable fate. While somewhat exploitative, these works at least centered the twins' own experiences.

Modern Media – From Sensationalism to Human Interest: In the late 20th century, as medical advances made separation more possible and conjoined births more publicized, media coverage often revolved around surgical drama or human-interest inspiration. When conjoined twin infants are in the news, it is frequently because of separation surgeries – celebrated as marvels of modern medicine when successful ("Twins separated in 20-hour surgery, go home healthy") or debated when risky (as in the Bijani case, which was widely reported with headlines highlighting the ethical quandary of their attempted separation 115 16). Adult conjoined twins who remain together, however, tend to enter the media on their own terms. For example, Lori and George Schappell gave interviews over the years focusing on how they live day-to-day – emphasizing personal stories rather than medical details. A CBS news obituary noted how the twins "kept separate lives and let each other pursue their own interests," even providing quotes of them explaining how

they achieve privacy and independence 117 34. Such coverage highlights their agency and personalities, not just their condition.

Abby and Brittany Hensel's media journey is particularly illustrative of evolving representation. They first appeared on TV in childhood to satisfy public curiosity, but with careful handling by their parents and media hosts who allowed the girls to speak for themselves. The twins later participated in documentaries (*Joined for Life* on TLC, *Extraordinary People* on Discovery Health) that showed everything from how they coordinate physical activities to their distinct hobbies and disagreements – portraying them as well-rounded individuals. In 2012, their short TLC reality series *Abby & Brittany* stepped further into the realm of entertainment, following them as young adults doing things like job hunting and traveling. The tone was largely respectful and upbeat, aiming to normalize their lives, though some critics worried any reality show inherently toes a line with voyeurism. The Hensels were aware of that risk, which is likely why they have since withdrawn from public life except for occasional controlled updates (such as their recent TikTok educational video ⁴⁹). They have expressed frustration with invasive attention – e.g. people asking overly personal questions or treating them as a single unit ("Do you have a boyfriend?" addressed to both at once, etc.) ⁴⁵. In response, they have often educated reporters on how to address them properly (making sure to use their individual names) and spoken out about boundaries.

One interesting facet of media representation is language. Journalists and the public sometimes stumble over pronouns and descriptors: Do we say "they" or "she" when referring to conjoined twins? In writing about Abby and Brittany, for instance, some outlets erroneously used singular ("she") which the twins and their family discouraged because it undermines their twoness. In academic discourse, conjoined twins are *always* treated as distinct persons, but in casual speech people sometimes implicitly treat them as one entity, especially if the twins habitually act in unison. Part of the twins' own advocacy is insisting on their twinned-but-separate identity being acknowledged in how others speak to and about them ¹¹⁸.

Privacy and Exploitation Concerns: Conjoined twin adults, especially those who are public figures, face the challenge of maintaining privacy. The very fact that any aspect of their life – even something as simple as grocery shopping - might be fascinating to outsiders means they often have to field unwanted attention. Some, like the Schappells, relayed that they developed a bit of a thick skin and humor about it; they occasionally appeared at Ripley's Believe It or Not events or disability forums, where they knew people were curious, but they balanced that with firm control over personal aspects of their life 119 34. In their own words: "People who are conjoined can have a very private life... if you love the person you're with and respect them, you give them privacy and compromise" 34 120. This statement, made by Lori and George, was both a message to the public (that conjoined people are entitled to privacy) and to other conjoined twins or caregivers (that internal respect is key). The Hogan twins' family in Canada provides another perspective: they allowed media documentation when the girls were children to help raise support and awareness, but once the girls hit adolescence, the family pulled back entirely. By the girls' early teen years, they decided no more images or updates would be shared unless the twins themselves chose to in the future 106 107. This kind of protective stance is increasingly common as families of conjoined twins navigate between benefiting from public interest (for fundraising or educational purposes) and avoiding the exploitation or loss of control that can come with overexposure.

In popular culture, conjoined twins have been featured in novels, movies, and even musicals – often as metaphors or symbols. The Broadway musical *Side Show* (1997) was inspired by Daisy and Violet Hilton's lives, portraying conjoined twins as the heart of a story about love and acceptance. While fictionalized, it brought a more empathetic and humanized image of conjoined twins to theater audiences. However, some

depictions still veer into the grotesque or comic. For example, Hollywood films have occasionally used conjoined twins as comic relief or horror elements (*Stuck on You*, a 2003 comedy, or the twins in *American Horror Story: Freak Show*). These representations can be double-edged: they keep conjoined twins in the public imagination, but they may perpetuate stereotypes or trivialize the real challenges faced by twins. Conjoined twins themselves rarely see accurate reflections of their lives in fiction, which is why their own voices in media (through interviews or memoirs) remain so vital to shape the narrative.

Encouragingly, the discourse in scholarly and ethical circles has shifted to treating conjoined twins not as problems to be solved, but as persons to be understood. Bioethicists write about them in terms of personhood and rights, disability scholars include their experiences to question norms about bodily autonomy, and sociologists examine how they integrate into communities or face prejudice. This more nuanced public discourse trickles down to general awareness. When the Hensels re-emerged on social media recently after a period of silence, the coverage in mainstream outlets like *People* or *E! Online* was largely positive and focused on their achievements (e.g., "Conjoined Twins Abby and Brittany are now teachers, living fulfilling adult lives") ¹²¹. This is a far cry from the pitiful or freakish tone one might have seen a century ago.

Navigating Identity in Public: Adult conjoined twins often become inadvertent advocates. By simply living their lives openly, they educate others on an alternative mode of human existence. Many embrace this role to a degree, as it can help them function in society – the more people in their community understand them, the easier daily interactions become. For instance, the Hensels allowed a BBC documentary during their college years that showed how classmates and professors interacted with them normally after an initial adjustment period, which in turn helps viewers realize that integration is possible and beneficial. Conjoined twins also sometimes speak at medical conferences or disability forums, providing their perspective to professionals. Such involvement is crucial because historically decisions about them were made *for* them by doctors or showmen; today, they claim their narrative. As Helena Franzén observed, finding the "voices of conjoined twins themselves" is challenging but necessary to avoid a one-sided narrative by outsiders 122 123. Conjoined twins who articulate their experiences help reclaim their identity from objectification.

In terms of public identity, conjoined twins might choose to present as a unit in some contexts and as individuals in others. The Hensel twins, for example, share social media accounts and often sign jointly as "Abby & Brittany" when addressing their fans or students, emphasizing their togetherness. Yet, those who know them personally also address them separately as Abby or Britty. This dual identity is something they manage fluidly, expecting the respect of being acknowledged as two, but also pragmatically aware that many aspects of their life are shared. This fluid negotiation of identity is perhaps one of the most intriguing sociological aspects of conjoined twin life – it challenges the normative idea that one body equals one identity, showing that identity can be both plural and singular in lived reality.

In summary, media and public discourse around adult conjoined twins has evolved from exploitative spectacle to a more respectful, human-interest focus, but it remains a delicate space. The twins must guard their personal boundaries while engaging in a bit of public relations to ensure they are seen as *people* first, not medical marvels. Their navigation of identity – balancing their individuality with their permanent togetherness – continues to fascinate and instruct society about the diversity of human life. As conjoined twins increasingly share their own stories (through books, interviews, or online platforms), they contribute to a more ethical and empathetic understanding, one that honors both their extraordinary physical bond and their ordinary human aspirations.

Conclusion

Adult conjoined twins who remain unseparated present a living paradox that challenges many assumptions in medicine, ethics, and society. Through documented cases, we see that such twins can lead rich, fulfilling lives: they pursue education and careers, form relationships, and carve out personal identities, all while literally sharing their bodies with one another. The types of conjoinment – from thoracopagus to craniopagus – set the stage for what medical options are available, but they do not solely determine these twins' destinies. Equally important are the ethical decisions made by families and physicians, weighing the value of two independent lives against the risks of separation and the validity of a conjoined life. For those who remain together into adulthood, autonomy takes on a collective dimension: each twin's freedom is intertwined with her sister's, requiring continual cooperation and compromise.

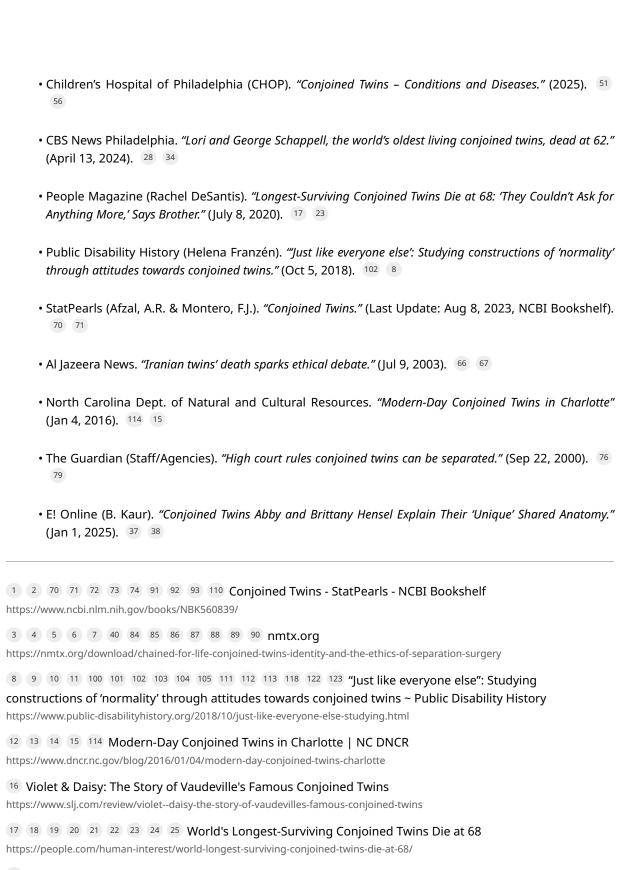
Psychologically and socially, conjoined twins demonstrate resilience and creativity. They develop profound bonds of empathy and often exhibit a witty, matter-of-fact approach to their situation. Yet they also face external challenges – from stares and invasive questions to institutional hurdles – that necessitate advocacy and adaptation. Culturally, their existence prompts society to reflect on concepts of normalcy, individuality, and connectedness. Representations of conjoined twins have moved toward greater sensitivity, guided in large part by the twins' own voices that insist on being seen as "just like everyone else" in the ways that truly matter [111] [105].

For scholars in bioethics, medicine, and sociology, adult conjoined twins underscore the importance of person-centered thinking. They are not merely cases or curiosities, but persons with rights, aspirations, and human dignity. The decision not to separate – whether made due to medical necessity or personal choice – can be understood as affirming a different but valid way of being in the world. As one observer eloquently put it, conjoined twins teach us about "the power of perspective" – challenging us to see two persons where others see one body, and to appreciate the extraordinary cooperation that makes their lives possible 11 34. They expand the boundaries of human experience, showing that individuality and togetherness are not mutually exclusive, but can coexist in the most literal way.

In closing, the stories of adult conjoined twins invite both awe and respect. Awe for the biological complexity and the human adaptability evidenced in their lives; respect for their personal agency and the oft-overlooked normalcy they achieve in day-to-day life. Studying these twins – from the Bunker brothers to the Hensel sisters – provides valuable insights into surgical ethics, the psychology of identity, and the social construction of normality. More importantly, it reminds us that human flourishing can take many forms. Whether separated or conjoined, what ultimately matters is that each individual (or pair of individuals in this case) has the opportunity to pursue their version of a good life, supported by informed medical care and surrounded by a society that recognizes their unique personhood. The conjoined twins who have reached adulthood without separation exemplify that being "joined for life" is not an absence of freedom, but rather a different expression of it – one where cooperation and companionship are elevated to the highest degree, and where the human spirit finds ways to thrive together against all odds.

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