

# Massachusetts General Hospital BMT Survivorship Program

## Chronic Graft Versus Host Disease

### What is chronic graft versus host disease (cGVHD)?

Chronic graft versus host disease (cGVHD) is a disease that is caused when cells from a donated stem cells attack the normal tissue of the transplant patient. Donor cells contain donor T-cells, a type of white blood cell. T-cells recognize what belongs in a patient's body and what does not. Sometimes donor T-cells may see the patient's organs and tissues as foreign and attack them.

### How common is cGVHD?

cGVHD is common after allogeneic transplant, affecting 3-6 out of every 10 people. That number can be higher or lower depending upon the age of the donor and/or recipient, stem cells vs. bone marrow vs. cord blood or haplo-identical as donor source, and type of transplant.

### When does cGVHD occur? How long does it last?

cGVHD usually occurs between 3-18 months after transplant. It may occur as late as 5-10 years after transplant. It may last a few months to a few years and may require treatment over a long time period.

### How is cGVHD treated?

cGVHD may be treated with topical medication and/or oral immuno-suppressive agents. Topical medications are the first treatment for most cGVHD types. It is important to take these medications as directed by your treatment team. Topical medication may help you avoid oral medications that can increase your infection risk and which have more side effects.

### What can I do to prevent cGVHD?

- Take all transplant medications as directed by your treatment team
- Protect yourself from direct sunlight by wearing sunscreen
- Avoid people with active cough and colds
- Report symptoms of cGVHD or infection early
- Drink a lot of water—ask your treatment team how much

### What organs are affected by cGVHD?

cGVHD most often affects the mouth and skin. It may also affect the eyes, lung, GI tract, liver, private parts, joints/muscles/tissues, nails and hair follicles. Symptoms may vary from mild to severe, and may affect one organ more than another.

## What symptoms may I experience? How are they treated?

Tell your BMT treatment team *right away* if you think you may have any symptoms of cGVHD.

### Mouth cGVHD:

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#### What are symptoms?

- Red or white spots or sores
- Dryness
- Sensitivity to cold/hot liquids
- Discomfort with citrus/spicy foods
- Pain with eating

#### How might my team treat this?

- Topical rinse with steroids and/or tacrolimus-3 to 4 times a day consistently
- Steroid gel + gauze pad for isolated sore areas or ulcers
- If lips are affected, tacrolimus ointment may help
- Pain medication as well as prescriptions for moisture/saliva production may be necessary at times, if those do not work, oral steroids are considered

#### What actions can I take to lessen side effects?

- Take all medication as directed
- Take part in Look Good Feel Better Programs
- Talk therapy
- Exercise — talk with your treatment team about an exercise plan that's right for you

### Skin cGVHD:

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#### What are symptoms?

- Dry itchy red rash
- Color (pigment) Changes
- Thick Skin
- Restrictions of joint or muscle movement
- Hair loss
- Brittle nails

#### How might my team treat this?

- Topical steroid creams and/or tacrolimus ointment twice a day
- Hydrolatum cream on top of other treatments

#### What actions can I take to lessen side effects?

- Take all medication as directed
- Take part in Look Good Feel Better Programs

## Eye cGVHD:

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### What are symptoms?

- Eyes feel dry, gritty, and itchy
- Cornea may appear red and inflamed
- Excessive tear production with dry eye
- Pain with eye opening or blinking

### How might my team treat this?

- Lubrication
- Medications to improve tear production
- Punctal occlusion
- Autologous serum tears
- Steroid or tacrolimus eye drops
- Antibiotic ointment
- Oral steroids immune-suppressive medications

### What actions can I take to lessen side effects?

- Take all medication as directed
- Use preservative free artificial tears 3-6 times per day tears (Bion Tears, Systane, Optive)
- For more severe cases, you may wish to apply a more intense lubrication prior to sleep, a preservative free gel is very useful 1-3 times per day (Tears Again Liquid Gel or Genteal Gel)
- Moisture chamber goggles or wrap-around sunglasses may also help maintain lubrication when you are outside in direct sunlight or windy environments

## Lung cGVHD:

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### What are symptoms?

- Dry cough
- Wheezing
- Shortness of breath with activities
- Fatigue

### How might my team treat this?

- Inhaled topical steroid
- Oral therapies

### What actions can I take to lessen side effects?

- Avoid smoking
- Avoid those with acute cough and cold symptoms

## Vaginal cGVHD:

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### What are symptoms?

- Vagina/vulvar dryness
- Burning
- Stinging
- Tightening of the vagina
- Pain with urination or intercourse

### How might my team treat this?

- Topical therapy with steroid cream
- Lubrication and moisture therapy

### What actions can I take to lessen side effects?

- Daily moisture with Replens, vitamin E oil, or olive oil
- Before sex, dilator therapy or manual stimulation topical water based or silicone lubrication should be used liberally to avoid tissue trauma (KY or Plur Glide)

## Penile cGVHD:

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### What are symptoms?

- Penile skin erythema
- Lacy white changes
- Skin irritation
- Pain with manual touch or intercourse

### How might my team treat this?

- Therapy with steroid cream to penile skin one to two times per day
- Steroid ointments may be prescribed a minimum of 3-4 weeks or continued until resolution

### What actions can I take to lessen side effects?

- Take all medication as directed

## GI cGVHD:

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### What are symptoms?

- Weight loss
- Difficulty swallowing
- Poor appetite
- Nausea
- Vomiting
- Chronic liquid stool

### How might my team treat this?

- Topical steroids with beclomethasone liquid or budesonide pills

### What actions can I take to lessen side effects?

- Write down any uncomfortable symptoms and what you have eaten. This will help your treatment team better treat your symptoms.